

## CHAPTER 5

### COMING TO GRIPS WITH DEPRESSION

(Ages 11-13 years – through 7<sup>th</sup> grade)

*I had an acquaintance from church who was a good bit older than I – she was completing her senior year of high school. I will call her Ellen. Ellen had already decided that she was going to go on to college and become a doctor. Now for some reason, she wanted to spend a couple of hours with me every Saturday. I am not sure why; but I imagine that she wanted to observe the symptoms of my MD to help prepare her for a medical career. One day when she came to visit in the spring, it was such a pretty day outside that we decided to take a walk. I got my parents permission, and we set out intending to just walk a couple blocks up the road and turn around and come back. When we got that far, however, I asked to go a little further, then a little further. I kept insisting that I was enjoying our walk and wanted to go on. She reluctantly agreed. Before we knew it we must have been at least a mile from the house – on the campus of the University of Alabama. We walked to a nearby pond and watched the ducks swim around for a while. But it was starting to get late, and she felt that we had better get on back.*

*We go back safely and in due time not to alarm anyone. And, while I seemed to have no problem in walking that far, the next day I had some serious problems. When I got up my legs were extremely sore, I had a sharp pain in the back of my knee, and when I tried to walk I had this feeling that my right leg was going to give out on me. When I told Mom and Dad about this situation, they concluded that I had been doing entirely too much walking. I did not realize that it was events like this that might actually get MD patients in a wheelchair well before this might be totally necessary. Exercise should be moderate and sustained, not excessive after long periods of inactivity. And yet, there are a variety of things that work against this ideal scenario: bad weather and lack of light during the winter, lack of opportunity, getting a cold, etc. It takes real effort to exercise in a consistent way, and the problems that others have in this regard are not foreign to the handicapped. Like other physical training, if it is to be effective, there must be a time set aside for this on a regularly scheduled basis, and this timing must be held to religiously. In retrospect, I realize that this was something that would have improved my situation, although there is no way of telling just how much longer I could have stayed out of the wheelchair had I improved in this regard: 3 months, six months, possibly a year at the most? Regardless, I feel now that it would have been well worth it.*

A couple weeks after my fifth grade let out (in 1978) I began to suffer with a bout of depression. The summer vacation had started with the first week spent visiting relatives in Louisiana. A combination of having to get back to the daily summer routine after this visit and just being worn out from the trip might have triggered the depression. But it was primed to be triggered by the knowledge in the back of my mind that my condition was about to worsen. It was at this time that I acquired my first wheelchair. I had known several kids who were wheelchair bound, and I recognized that this would some day be my fate. My forerunner, Kevin was also now wheelchair bound. However, as a young person, even six months seems an eternity, and it was not until my situation

had deteriorated to the point that I was spending considerable time in the wheelchair that the immediacy of it all hit home to me.

The wheelchair was needed just as much for my balance deficiency as it was for the fact that I could only walk a limited distance. The acquisition of this piece of equipment itself was not that traumatic because of the gradual stages in its use. At first it was only for long distances. Then, those distances got shorter and shorter. There were some places, such as at the pool, where my parents insisted that I use it, since the danger of hurting others or myself was relatively high there. Mom would push it to the edge of the water and then help me into the water. After the swimming was over one of the lifeguards would help put me back in the chair. In retrospect I can see that it was all of these events at this point that led me to my first prolonged spell of depression.

It seemed like it started on a Sunday afternoon, the day after we had gotten back from Louisiana. It is hard to explain ... like there was something in the air that had me down. Talking with my mother years later, she mentioned that it was in the spring of the year when they learned that I had Muscular Dystrophy (MD). She speculated that my having sensed their distress at this time might perhaps have made me associate bad news with the spring. So, perhaps a combination of these factors compounded the problem. At the time I did not really know the reason for my distress.

Missy and I were kept busy with unpacking from the trip, and the many other things that you have to do when you have been away for quite a while. So, even though I had a depressed feeling in the pit of my stomach, I did not have much time to dwell on it. It was really later on that night when everyone had gone to bed that I laid awake thinking about my situation. Suddenly, around ten o'clock, I could contain myself no longer and started sobbing uncontrollably. My parents heard and came into my room, but they could do nothing, since there was no apparent reason for my behavior. For that matter, even I did not know why I was crying.

Another part of this depression that was hard to explain was my recognition at this point that I had some responsibility to God. My parents had taken me to church all of my life, and I had a good understanding of most of the bible at this point. However, not having full maturity, I still was not sure of exactly what my responsibility to God was. This was still years before I was baptized into Christ, as it teaches in Romans 6:3. I do not recall what my parents said at this point, but I am sure that we did not get into the religious aspect of things. However, whatever they said, it was sufficient to calm me down and enable me to get a good night's sleep. Perhaps just knowing that they were there and that they were concerned about me was sufficient to ease my concerns at this point.

The next morning when I arose I still felt down ... depressed and sad ... but I was still able to control the crying. I did not do much to keep busy, and things started to seem bleak once again. I just sat back in the recliner and watched TV. Nothing was on that I really wanted to see, and I pretty much was just staring at the tube but thinking of my plight. Dad had gone on to work, his vacation being over. Mom recognized my situation was carrying over from the night before, and she did her best to try to get me involved in something ... anything. At my age, I did not realize that getting occupied in something would help the depression problem, and so I did little to help the

situation. Later on in the afternoon when the cartoons came on I could get distracted; but the morning programs left me cold.

During that week Mom took Missy and me to the theater. It was a Charlie Brown (Peanuts) movie, and it seemed to snap me out of it, at least for a while. However, it seemed like at night when the sun went down things came back down on me again. I would have periods of crying that were quite mysterious both to my parents and me. I was frustrated not only because of this interruption in my normal schedule, but also because I had no real idea of what was causing the problem. It seemed that it was a working of my suppressed subconscious. I just could not get over it. Later on I was to learn more about what caused this and deal with it more effectively, and I will discuss this at the appropriate time. However, at this point my parents were just as frustrated as I was.

After about a week the depression vanished as suddenly as it had arrived. Probably the main reason was summer school, which got my mind off of my condition and gave me some new challenges. They had a summer program that lasted the last two weeks of June, all of July, and the first two weeks of August in which handicapped students from throughout Tuscaloosa could be given special classes. It was a program not only to help the handicapped and give them something to do during the summer, but also to help student teachers get their certificates. This gave some a head start to getting their intern experience, and others who were finishing just needed a few more months to qualify. The main reason that I was going to summer school was that there were very few kids my age in my neighborhood, since it was a rather old neighborhood. There were only two girls across the street, and I was not too interested in associating with girls at this point. So summer school enabled me to interact with other kids, which, in retrospect, was the greatest cure for my depressed state earlier in the summer.

The summer school was at an excellent facility not too far from our house. Dad would usually drop me off on his way to work, and Mom would pick me up after school. Some of my friends from school – Sherri and Doug – were also involved in the summer program. So I had friends to start with and met several others who became friends as the summer unfolded. One that I especially remember was a young fellow (about 8) named Jimmy. Jimmy had Spina Biffida and spent most of his time in a wheelchair. We soon became the best of friends; however, for the first few weeks our relationship was a bit strained. This was probably because we were so much alike. We both had similar senses of humor and enjoyed having fun, being recent graduates of the Don Rickles academy of insults. As such, we spent a good deal of our time together trying to out-insult each other. In addition, one of the teacher's aids had a very friendly attitude, and we both enjoyed her and vied for her attention.

At different stages of the class, the teacher would pick various students who would work with the aids to help her with her work. We would always fight to see who would get to work with our favorite aid. While we did a lot of math and reading, summer school was not just work. There were a number of fun activities and games that we played that broke things up quite nicely. We had a lot of free time to socialize together and just have fun.

One of the theaters in town had a summer matinee that the students could get in at a reduced price. Every Wednesday our school would borrow a van and take us to this matinee. Some of the

main movies that come to my mind were based on the exploits of Robinson Crusoe and Huckleberry Finn. All of this tended to pull me out of my initial depressed state so that the summer of 1978 turned out to be an enjoyable and memorable experience. I regret to think what life would have been like, however, without the luxury of summer school.

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As I entered the sixth grade in the Fall of 1978 there were many changes in my lifestyle. My MD condition deteriorated to the point that by Christmas of that year I was totally confined to the wheelchair. Concurrent with this deterioration, there were also a number of changes that were being made in school. Special ed was becoming over-crowded, and the city board decided to expand the program to another building. They decided that those under the age of 12 would remain in the old facility, while those aged 12 and above would move to a new one that was being built. They went ahead and hired the teachers for the new facility despite the fact that the construction had not been completed. So there was no choice but to keep the students together in the crowded conditions for the fall semester, although we did have additional teachers.

To better organize us for when the new facility opened its doors, they split our class into two different classrooms. Moving into the “older” class with me was Sherri and Pam. A few other students from our old classroom came along as well, but Doug was left behind. However, since the four of us had become quite close during the previous school year, we continued to see quite a bit of each other outside of school. Also, since our classes were in the same building that semester, I continued to spend time with them (especially on the playground since both classes had recess at the same time). So, my relationships with Doug, Sherri and Pam continued to develop.

Our new teacher had served as a student teacher when I was in the fourth grade. He had spent some time in Montgomery before getting the job here as a result of our expansion. While he was quite nice, I found him somewhat more impatient than the teachers that I had had since the second grade. Patience is essential in a special ed environment, and I came to believe that he should not be a special ed teacher. Physical handicaps – and perhaps even more with learning disabilities – require a degree of tolerance that the average teacher does not require. While I believe that he eventually went on to another job outside of special ed, we had him for three years.

Things were quite crowded, not only with the combined students but also with the additional teachers. Our classroom was wherever we could find a corner of a room. At one point we were meeting in the “gymnasium” area, which was about the size of two normal classrooms without “conveniences” such as blackboards, bulletin boards or a sink to wash up for lunch. Later, toward the end of the semester, we were able to move into a regular classroom.

During our first semester we did not have enough textbooks, since they underestimated how many we would need and did not want to send too many if they would need to be moved again soon. One of my favorite classes at this time was history. This was one of those classes in which we had only a teacher and one textbook. Unfortunately, he usually just read the textbook to the students. It was quite difficult to listen to this and to get anything out of the class. We did establish a few things. For example, I found of interest the four Indian tribes that inhabited Alabama before

the white man came: Cherokee, Choctaws, Chickasaw and Creeks. It was interesting that the area where Tuscaloosa is now located was inhabited by the Choctaws.

One of the students that had joined our classroom had suffered from some kind of skin disease. It was not life threatening, but it left scars on her face like her skin was peeling. She had been in the regular school system, but her *normal* peers did not know what to make of the condition. And, as children are prone to do, they tended to harass her about her condition, and for some reason her teacher made her sit at a desk away from the other students. So, she decided to come to the special ed class so that she would be treated normally (interesting play on words).

While all of that would seem to be quite sympathetic to this poor girl, in reality she was mean as a skunk (if it can be said that a skunk is mean). No matter how much you attempted to establish a friendly relationship with her, she would just turn her wrath on you and make your life miserable. I will say that occasionally she would have a good day, which led me to believe that it was just her condition that had gotten through to her, and she was not inherently bad. But I recognized that having a handicap does not, of necessity, make a person pleasant. In fact, if you think about it, human nature works just to the contrary. Those of us who are handicapped must rise above this inherent tendency toward blaming the rest of the world if we are to get acceptance even from our fellow handicapped peers.

As **sixth grade** progressed, I began working my way toward wheelchair confinement without really noticing it. Keeping my balance was turning into far more of a problem than an inconvenience. There were times when I would be standing and barely moving, my leg would give out and I would go crashing to the ground. It got to the point that at home I had a hard time with my chores. One of them was loading and unloading the dishwasher. One rule that my mother laid down was that I was not to touch any of the knives for fear of losing my balance and falling on it.

A turning point came one morning when, going to the kitchen for breakfast, I passed close to a card table. Suddenly without warning I fell ramming one of the chairs of the card table up under my arm, causing considerable pain. That night when I came home from school my mother suggested that when it came time to eat that I just pull my wheelchair up to the table instead of using the regular chair.

Another key indicator at this time involved my difficulty getting dressed. I could get my shirts on without any problem. However, I had considerable difficulty getting my pants on. I could get one leg into the pants with no problem. However, standing on one leg (a task most take for granted) was next to impossible for me at this point. My father noticed that I was having difficulty and asked me if I needed help. I reluctantly agreed, thinking that this was just one of those days when I was having a hard time getting started. I remember leaning on the dresser and he would pull the pants up for me. Unfortunately, this was not just one of those days. For, the next day I had problems as well, and soon I found that not needing help was the exception rather than the rule.

Interestingly, none of these events, within themselves, was traumatic in any way. I was a bit confused about having to have help getting dressed every morning, but, for example, the idea of

pulling the wheelchair up to the table was not so bad. I even thought it was fun, and a chance to see how the “other half” lived.

But, there were some traumatic events. My parents noticed that I was having more and more problems getting on and off the bus even though I was using the lift. I was still walking out to the bus and using the lift rather than the steps to get on. They were concerned that I might lose my balance and perhaps hurt myself seriously by falling off of the lift after it was up. So, they suggested that I ride the bus in my wheelchair. This was not what I considered fun any more – this was serious. I first thought they were accusing me of being lazy. I was concerned that my friends and teachers would think that I was trying to call attention to myself. So, I argued back and forth with my parents, and things got somewhat heated. But, of course, the inevitable won out. Arguing could not change reality, and I recognized that their main concern was for my welfare. So, reluctantly I agreed to get in the chair while they pushed me out to the bus. I would get up on the bus using the lift, and then they would lock down the chair within the bus.

One of the students agreed to push me to my classroom. As I entered the classroom for the first time in the wheelchair, I stated for all to hear: “Now before you say anything I want you to realize that this is my mother’s idea, not mine.” I wanted to be spared seeing everyone with their jaws dropped open. I expected a lot of comments, but nothing was forthcoming, so I figured that my mother must have called them in advance to tell them that I was going to be in my wheelchair, and the teacher had relayed the message to my classmates. The students were quite nice about it, and the transition occurred without incident.

Actually, the wheelchair was more of a nuisance than anything else. Usually after getting to the classroom I would park the chair in the corner, get out, and go about my everyday activities. Things were pretty normal then, until after the school day was over and I would get the chair back out and reverse the process. Eventually as the semester wore on, I would find myself using the wheelchair more and more.

One day I was walking with my classmates on the way back from lunch. Less than half way down the hall I noticed that my legs were beginning to bother me, and it was slowing down my walking. The teacher noticed this, and asked me if I wanted him to go and get my wheelchair. I said no at first, but when I realized that I was about to lose it, I reluctantly agreed for him to help me out. One of the teacher’s aids went and got it, and they pushed me back to the classroom. As far as I can tell or remember, that was the very last time that I can recall walking. I may have inadvertently taken a few steps now and again without really thinking about it, but this single event stands out in my mind as the turning point of my confinement to the wheelchair.

Strangely, though, looking back at this event, it was not as catastrophic as one might think. It was not like one day I was walking around and the next day I was confined to the wheelchair. It was a very gradual thing, and even when it became final in the practical sense of the word, it did not register as such in my conscious mind. I never had the stark realization that I was never going to walk again until I was in the wheelchair for several months, but by then I was transitioned into it. It does not take long before you consider the wheelchair as an extension of your body.

At the time when the “day of recognition” came there was only one or two weeks left before Christmas vacation. And, wheelchair or no wheelchair, this was an event that got me excited, distracting me considerably from my other problems. Like most kids, Christmas is one of my favorite holidays, and I was looking forward to our usual trip to Louisiana and meeting with relatives that I had not seen in nearly six months.

Another factor that kept this from being too traumatic was that I considered the wheelchair to be fun. Perhaps this was a spin that my parents put on it, or maybe it was just something in my own nature. One thing, I had been around kids confined to wheelchairs for some time, and there was a curiosity about how they got along totally without the ability to walk. After all, when we were children, did we not all close our eyes and try walking around just to see how it would be to be blind? The first time that I had to spend a whole day in a wheelchair the reality of what it was really like came through in a big way. Even then I was thinking that I could always just get up and walk around if I really wanted to. But then, why bother? Things were not bad, and there was no great compelling reason to get up on my shaky legs. So I gradually began to accept the fact that I would probably never walk again.

In the meantime I was having fun in the wheelchair since there was a novelty to being in it – a type of challenge to see if I could accomplish the normal tasks. It was somewhat of an improvement over, and certainly much more reliable than, my uncertain legs. I did not have to worry about losing my balance, falling and hurting myself, or being an embarrassment. The wheelchair also brought more attention to me, since my parents had to help me out more and more. I recognize that this was a childish and rather selfish incentive at the time, but it would be dishonest of me to hide it, and it is a factor with which parents of handicapped children should be aware. There is an optimal degree of attention that can be given. Either too much or too little can be harmful.

My cousin was completing almost the second year of total confinement to his wheelchair. For as far back as I can remember there had always been a healthy rivalry between Kevin and myself – sort of a “keeping up with the Joneses” type of thing. Whatever Kevin had, I wanted one just like it, and vice versa. Soon my grandparents learned that whatever they got for one of us, it was best to get for the other as well. So the wheelchair transition was to me just a continuation of our follow-the-leader game. It was not that traumatic a transition. Perhaps the perils and pain of using my legs made the wheelchair all the more inviting.

I relate the cause of my depression to many of the other losses that I was sustaining concurrently with the loss of my ability to walk. All the things that I did for which I needed help – being helped into bed, taking a bath or being helped in the bathroom – I related these things to a lot of the things that I had heard people mention about Kevin. Interesting, when I heard these things I just blew them off. They did not relate to me at the time, and to a young person, six months is an eternity. But now as they started to become a reality I started to recall them. Kevin and I really never discussed these things since our relationship was one of companionship and mutual entertainment, not deep discussions on the ramifications of our common disease. That was irrelevant to us. Obviously, we had much in common that bonded us together in a very special way.

The main point is that the peer pressure thing was a plus. I could not let Kevin out-do me. Now I could relate to him and have something to tell him as well. He had a two-year head start on me; but now it was my turn to begin catching up. When I saw him the next time he did have some advice for me as to how to make myself more comfortable. For example, he had cushions that he could move around under him to relieve the constant pressure to one part of his body. That was a great idea, and I soon acquired some cushions of my own. Kevin had cushions, I had cushions. Then there was the matter of relieving the soreness on the back or your legs. Kevin had discovered that if you put sheepskin under your knees this would relieve this problem, and he sent me some. Kevin had sheepskin, I had sheepskin. This type of tit-for-tat relating to each other gave both of us a lift. I was not, at the time, obsessed with comparing myself with other normal kids; I recall more comparing myself with Kevin, and not feeling so awfully bad in that regard. I knew that he had put up with it and overcome; so could I.

Kevin and I had other things in common that weren't so trivial as cushions of sheepskins. We both needed help in the bathroom and getting dressed as well as getting in and out of bed. We rarely discussed the more serious aspects of our conditions with one another – we were always having too much fun. However, just knowing that we could relate to each other in this regard seemed to be enough.

When I was first confined to the wheelchair I was still limber enough so that my parents could help me get onto the floor, and I could crawl on my elbows and knees and move around in this way. This gave me a certain degree of freedom that also kept the point of wheelchair confinement from being so traumatic. Perhaps another reason that I was not overly bothered by it was that it was the winter of the year and there was not a whole lot to do outside at this point. There were a lot of circumstances that played together to mitigate the immediate impact. Still, subconscious baggage was accumulating.

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As November came around I looked forward to the celebration of my twelfth birthday. My birthday fell on a school day, and there was another student in the class who had a birthday about the same time that I did. So, the teacher decided that instead of having two separate birthday parties they would just combine them into one on a common day that we would pick in the middle of November between our two birth dates. I was a little upset at not having my own special party, but figured that this would be better than nothing.

On my birthday, after we had finished lunch, the teacher asked me to get together with him and decide what decorations we would put on the bulletin board. This struck me as strange, since he had never mentioned this before. Even stranger was the teacher asking me to accompany him to the teacher's lounge. Well, I went along with it, thinking that the whole thing was boring. When I got there he just flipped through magazines looking for something to put on the board. After about ten or fifteen minutes (which seemed like an hour), he got up and said that was enough. As we approached the classroom I noticed the lights went off, and when we went in he said halfheartedly: "I wonder why the lights are off, I guess everyone is asleep in here." Obviously, you are way ahead of me – the lights came on and everyone yelled: "Surprise!!!" They had even invited my mother. So

the “common party” thing had just been a ploy to divert my attention on my birthday, since my birthday came before the date that we had set.

As we were celebrating and eating cake I was thinking: “Next year I will be a teenager.” This brought all kinds of images to my mind: loud music, going to the mall, ... cruising all over town. However, at that time I did not realize that by the time I would become a teenager I would be totally confined to a wheelchair. All of these dreams that I had were going to remain just that – dreams.

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We had a Christmas party at the school before the semester was over that year. Each student would bring a present for one of the others, and I was fortunate to get my first transistor radio. It fit in my pocket, and that was exciting enough for me to obscure much of the concern with my transition to the wheelchair. I carried it around with me and played it at all hours of the day and night. Between this and the excitement of going to Louisiana, I was almost entirely distracted from the realization that my walking days were all but over.

I dare not omit the positive effect that my parents had on me at this particular time. There is no doubt in my mind that this had to be one of the saddest days of their lives, since they were fully aware of the global picture and the full impact of its meaning. However, they managed to keep this from me in a way that I did not even have an inkling of their concern. I can only imagine the negative impact that this would have had on me if they felt compelled to share their concern with me. If they had expressed sympathy or had tried to “prepare” me for this major turn of events it might have been catastrophic, given the deep depression that I had experienced just a few months before. As it was, I barely even noticed what was happening, and to some extent even viewed the whole situation as a fun thing.

Instead of worrying over it we packed up and headed out for Louisiana. This time they had to rent a U-Haul luggage carrier for the roof so that they could put the wheelchair in the trunk. When we first arrived at my Grandparent’s house they unfolded the chair and put me in it. I recall thinking it strange that my cousin Christie (Kevin’s sister) automatically knew what to do. She grabbed the foot pieces, clipped them onto the chair, and put my feet in them. It was fairly obvious that she was quite experienced in dealing with the wheelchair bound, and I realized what a great help she must have been to Kevin and the rest of their family. I did not resent her assistance in any way; but that is me – perhaps others would.

My grandparents and cousins were quite supportive in their attitudes. They too knew how to deal with the handicapped, even to the handling of the sensitive emotional aspects. Kevin and I grew much closer, since now we had even more in common. For this (Christmas of 1978) visit, it was quite cold outside so we spent most of the time inside listening to records and playing with matchbox cars and such as that. There were a couple of days when we were able to get out. Kevin had an electric wheelchair, while mine was strictly manual. This presented a problem since he could move around at will while I was fairly confined as to how far I could push myself. My arms were losing their strength as well, and my range was limited. To fix this problem we took parts of

our seatbelts and linked them together so he could tow me around the yard. It also worked quite well at the shopping mall, since our interests in shopping were quite similar as well.

There were increasing inconveniences. The bed at my grandparents' house was a lot lower, so Dad had problems getting me up. And they were not set up very well for my taking a bath. As I recall, this was the first time that I had to take a sponge bath. If you have never been through that experience just try it sometime. Great if you love the cold. There was also difficulty in getting into Grama Joyce's house (my paternal grandmother), since it was up three large steps that could not be negotiated in the wheelchair. However, Paw Paw Fairchild (my maternal grandfather) made a set of runners out of wood to traverse this. These boards were placed over steps, and they would assist Dad as he pushed me up. It made me nervous, and I would be sure that I had fastened my seatbelt before each of these shots to the moon. However, as time went by I became less and less nervous, and we never had a single crash.

It was not until we arrived back home (late December, 1978) after our Christmas vacation some of the negative psychological effects began to set in. I was home again without many distractions, just as in the previous spring when school had let out. One of the first things that hit me is the wondering of what my friends were going to think when I went back to school and I would be spending *all*, not just part, of the day in the wheelchair. In retrospect I now realize that they could probably have cared less, since they had their own problems that they were worrying about. However, peer pressure is a tough thing for all young people (handicapped or not), and it was a serious concern to me at this point.

Similarly, I was concerned with what the people at church were going to think about it. I was greatly relieved when I received a card from my Sunday-school teacher stating that they had missed me for the past couple of Sundays, thinking that I was sick. She also mentioned that she had heard that I was spending all of my time in the wheelchair now, and went on to say that this was OK with them, since they would rather have me there in my wheelchair than to not be there at all. This was not only appreciated as a fine gesture on her part, but it relieved me entirely from the concern of going back to church, and it had its residual effect in giving me courage to go back to school as well.

School was not without its problems, however. When I was in the 3<sup>rd</sup> or 4<sup>th</sup> grades I felt that the time that I spent in the wheelchair was neat, since subconsciously I was saying: "I am one of you now." However, now that I had no choice but to be in the wheelchair, I had fears that they would think that I was just a copycat or just plain lazy. Surprisingly, when I went back, no one said a single word to me about it. When I decided that I could contain myself no longer, I resolved to make a statement myself. In our free period, I was sitting next to Pam, with no one else around. I began to explain to her why I was in a wheelchair – that this was part of the MD process; even though you start out walking, eventually you end up in a wheelchair. To my surprise she already seemed to know this, and seemed relatively unconcerned about it. This had a very positive effect on me, since I rationalized that if she could so readily accept it, then so could everyone else. Thus, the subject never came up again. *Years later Pam was to tell me that she knew even when I was walking that I would eventually end up in a wheelchair. How she kept this information from me (i.e., that she knew about it) during the many years of our friendship, I do not know. I feel strongly*

*that if I had that type of information about someone, it would be hard for me not to want to discuss this with them.*

Since I could no longer roam all over the house with ease, my parents decided to place a card table in the den close to the TV set so that I could put my books, tapes and other things on it and pretty much perform most of my activities right there. So all of my drawing, reading and writing was done right there, and from time to time I might ask Missy or one of my parents to get me something from the other rooms. The card table was a gift from my grandmother who obtained it by redeeming her extensive green stamp collection.

Another aid, now that I was in a wheelchair, was what I nick-named the goody-graber. It had a pulley on it and a clasp at one end, so when I dropped something on the floor I could retrieve it with this extension to my arm. I would use it to pick up my pens, papers or whatever else I would be prone to drop. It was nice not having to call on my parents or sister every time that I dropped something, so this gave me additional independence.

One of the real downsides of being in a wheelchair is that loss of control of your own schedule. While I was walking I could go to the bathroom whenever I needed to. Now it was a radically different story, since I needed help. I realized that Mom and Dad could not just drop everything that they are doing and help you out on the spot (unless, of course it was an emergency). Other activities required assistance as well, like taking a bath. Before I could take one any time I felt like it – morning, noon or night. Now bathing has turned into a long, drawn-out process that had to be fit into my parents' schedules. Rolling around on wheels was not the difficult part. This loss of control of being able to do what you wanted to do – even the smallest things – when you wanted to do them, was the part that was most distressing. For example, I would have to go to the bathroom as soon as I got up, when I got home, and before going to bed. Similarly, bath time was almost strictly before I went to bed now. It was now much more of a regimented life due to the loss of control over my legs.

The first thing that my parents did to accommodate my loss of control was to install a hydraulic lift with a canvas harness in the bathtub in order to enable me to more easily take a bath. I would get into it on the outside of the bathtub and swing over the water and then they would lower me into the water. Once I was finished with the bath, the process was reversed and most of the water drained right through the canvas. I would swing back out and be lifted back into the wheelchair. As a boy I was not fond of baths, and this did nothing to further endear me to the process.

When the lift first arrived my mother tried it out on my sister first, since she knew that if it got stuck my sister could just jump out of it. Missy thought that this would be great fun as she jumped into the harness with abandon. Mom could not quite figure out how to do it at first and pushed the down button dumping her on the floor. Then she tried the up button and Missy began swinging over the tub. "Stop ... stop ... STOP!!!" she screeched as she apparently thought she was going through the roof. Mom hit the down button almost instantly giving Missy a shot of adrenaline that made her scream. Somehow I never got the roller-coaster ride. I guess Mom got adequate practice on Missy, who was more anxious to get off the lift than she was to get on it.

Actually, the lift was relatively slow, and the process was so long and time consuming that it took about an hour from start to finish. It was just too much time to take every day, so we compromised and I began to get my bath every other day.

Another major change was related to the way that I would dress now that I was in a wheelchair. Before blue jeans had always been my staple, and if not, I had no interest in wearing them. But, since blue jeans fit so tight it would be difficult for me to sit in them all day. It was also difficult for me to snap the snaps that most of them used to have. My father would have trouble putting them on me in the morning while I was still in bed. We were not sure how to handle this. The teacher at school recommended that I wear sweat pants or a jogging suit. So we tried this. While they fit comfortably, they were so loose that when I was at school I would get the feeling that perhaps I had forgotten to change out of my pajama bottoms. This just gave me a generally uncomfortable feeling subconsciously that was difficult for me to get over. So, after about three weeks Mom got me some larger khaki-type pants that seemed to be a good compromise. They had the advantage of being both flexible and having hooks rather than snaps, which made things much easier for me to handle.

Being confined to a wheelchair also brought a number of transportation problems. Before I could just slip into the car with no problem getting in and out. Now I would have to be lifted out of the chair and placed into the car, and then there was always the problem of taking the wheelchair along, usually in the trunk. Then, when we got there the process would be reversed.

At this point Kevin's parents had obtained a van with a lift in it to accommodate this. The main advantage of this was that they did not have to lift him out of his chair, which could be rough on the back for people who were not used to that type of manual labor. So just wheel the chair onto the lift, push the button, shut the door and you are ready to go.

My parents were thinking about a van at this point, but it was quite expensive, so they put it off as long as possible. I was a great proponent of getting a van, since it would result in my not having to be as much of a physical strain on them. I argued with them, and got through on one Sunday when we were going to church. It was in the wheelchair, into the car, out of the car, into the church building, out of the church building, into the car, etc. Not only that but on this occasion they decided to go out to get something to eat afterward, so the process had to be repeated two more times. It was in this weakened condition, as Dad was lifting the wheelchair out of the trunk for the umpteenth time, that he began saying: "I will be glad when we get a van and don't have to go through this procedure every Sunday."

It was not long after this that they purchased the van – still during the spring of my 6<sup>th</sup> grade year. The van was two shades of blue, and these types of vehicles were quite popular for recreational purposes, especially in the south at this time. Getting the van was an easy part; the hard part was getting the lift into it. So, before we got the lift, we were stuck with the van with essentially no way for me to get in and out of it. For, if we went through the process of lifting in and out, this would defeat the purpose of it to start with. My grandfather came to the rescue as he had in the case of cousin Kevin before they got their lift installed. He took two large boards and cut them appropriately so that they became runners that we could use to roll the wheelchair into the van. This was

a temporary fix until we could get the lift, which would be safer and quicker. However, it did allow the van to serve its purpose until the lift could get installed.

Once we got this set up, the first two trips that we made to the mall with Mom and Missy were quite interesting. I was anxious to get going to the mall, so once I wheeled down the runners, I was off and rolling. However, Mom and Missy were stuck with the job of putting the “bridge” back into the van, which was not all that trivial for them, since the boards had to be stout and heavy to hold me. However, Missy insisted that she would handle the job single-handedly. I wondered about why she would volunteer for this difficult task for several days, but I concluded that she had my cousin Christie as a role model, since she seemed to assume many of the responsibilities for Kevin.

Meanwhile my parents discovered one certain type of lift that was popular. It was hydraulic, but not like the one on the school bus. The entire thing sat within the van. I could hold on to a bar that was at one side of it, and it would lift up just a little. Then it would swing outside, and it could be lowered to the ground. The process would be reversed to get me back in. My parents did not know anything about lifts at this time, but they knew a man who had lost the lower part of his legs in World War II who had a lift of this type, and he checked it out for us. Mom and Dad reminded me not to ask him anything about the war since they felt that he might not wish to remember these things. Not that I needed to be warned. I had been watching MASH for about five years and had become sensitized to the fact that many people do not wish to talk about their war experiences. And, while some do, the safe thing is to just let them bring it up. As it turned out he was a very talkative person and he emphasized that handicapped people have their rights, and that we need to be proactive in using our rights to get out and not just stay cooped up in the house all of the time.

He mentioned some things that I had never thought of. For example, if a handicapped person is in a house that does not have a ramp and there is a fire, the firemen will never know that there is a handicapped person in the house. So the ramp serves this purpose in addition to its primary role of enabling the person to get out and interact with the outside. He really impressed me when he stated that *everyone* has some sort of handicap. Some are not as tall, some are not as smart, others have personality problems, and, of course, there are all kinds of physical problems. But no one is immune – the person who recognizes no shortcomings might very well have a problem with ego. He pointed at my parent’s glasses and stated that without them they probably could not find their way home in the dark, which was not far off the mark. This made a very strong impression on me since I had never really thought of it that way. I have used the word “normal” throughout this book to refer to people who do not have a noticeable handicap. However, there is no such thing as a perfectly normal person.

With his advice, they selected the lift and got it installed in the van. This certainly made me feel a lot better, since now I would not have to impose on anyone in order to get around. It seemed much like it was before I became confined to the wheelchair in this regard, at least.

There were a couple of other things that tended to divert my attention from my deteriorating condition, and this made the transition somewhat easier. One of the main things was the opening of

the new school, and I spent the second semester of the sixth grade at this new facility, called Oak Hill School. Coming along with me were most of my friends from the old classroom. The only one that was left behind was Doug, and that was disappointing. However, I was quite excited about the situation, and it was a good distraction from the negative things that were happening.

The new school was an excellent facility, especially for the handicapped. It had a full sized gymnasium, an indoor swimming pool that could be heated in the winter, a shop room for woodworking and other crafts. It also had a home economics room in which we learned about how to manage a household budget, with a supplementary room in the back that looked like a small apartment. It had a bed, living room study, bathroom (complete with bathtub) and kitchen. This was extremely beneficial in that we had classes for the handicapped on methods for taking care of ourselves. This included such things as sewing, making up the bed, cleaning the house, and cooking. At first my male pride made me reluctant to join this activity, but eventually I began to enjoy it as much as everyone else did. I especially liked the cooking part of it, because afterward we could usually eat what we cooked. We had a few major disasters that had to be thrown out; but for the most part we came up with some quite edible cuisine. One time our home economics teacher had us make cupcakes. My job was to put icing on top of the cupcakes. From time to time when no one was looking I would accidentally on purpose spill a little icing on the table so that I could stick my finger in it and lick it off.

The facility also had carpeting and central air conditioning, which was essential for the weather that we had in Alabama during the spring – at least most people now would say so. The carpet and dryness of the air conditioning system led to a situation that static electricity built up on you from sliding or even rolling across the carpeted floor, giving us a shock when we touched anything metal. Everything there was so new that I associate this newness with the electricity that seemed to be all around.

The only disappointment with the new facility was that the swimming pool had not had the bugs worked out of it, so for the rest of the school year we were not allowed to go into swimming pool area, which was quite a let-down for most of the students. But there was enough of the rest of the facility to enjoy that having the swimming pool to look forward to was not so bad at all.

It was about this time that my mother entered the hospital for some major surgery. It took her about six months to recover from this. During the two weeks that Mom was in the hospital my grandmother came over from Louisiana and took over the house. Like most grandparents, especially those living far off, she did her best during those two weeks to spoil us rotten. Of course, we loved every minute of it.

One afternoon my sister and I came home from school and Grandma informed us that one of Dad's associates was bringing a zucchini casserole for us to eat that night. Missy and I looked at each other with the same-mirrored frown. Needless to say, we were not enthused. Somehow the words zucchini and casserole just do not go together – I mean, where's the meat? We do not expect veggies to be the main dish. So, as spoiled as we were, we let grandma know our displeasure in no uncertain terms. She reached compromise with us – if we would just let the wonderful woman leave it off and be quiet, she would figure out something for supper. So Missy and I held our peace

as she delivered the goods and then got back in the car and left the neighborhood – “Gross, sick, yuk ...” Our suggestions were graciously received by Grandma, who smuggled us off to nearest Dairy Queen where we got hamburgers, fries and milkshakes. As we were eating, Grandma said that it would be sad if the kind lady were to come by and see us stuffing our faces with such fare. However, the zucchini did not go to waste – Dad and Grandma finished it off just fine.

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Sometimes events intended to be most positive can backfire. The Special Olympics are intended to be a positive reinforcement to the self-esteem of the handicapped, and they most often are. However, their impact is mostly determined by the attitude of the participants, both the “athletes” and those who are administering the “contests.”

It was about midway through the spring semester of the sixth grade when I volunteered to participate in the Special Olympics. One of the events was a wheelchair race. This was one of the first attempts at Special Olympics for the volunteers at Tuscaloosa, and things were not well organized. They realized that there were some there who were extremely strong, so they made a rule that we were only allowed to use one hand. I was just getting used to the wheelchair, and there was no way that I could make it go in a straight line with just one hand. Most of the competitors had been in wheelchairs for some time and had developed very strong arm muscles. When they saw my plight they relaxed the rules and allowed me to use both hands, but this was of little help. Not only had I not been building up my arms, but my disease had weakened them to a considerable extent. The other kids took off like lightning bolts leaving just my female classmate and myself to battle it out for next to last.

Since I was just going around in circles they relaxed the rules on the spot and let me use both hands. I was way behind, but was gaining fast on my female classmate, and it looked like I would at least be able to retrieve some semblance of respectability. However, just as I was about to pass her they relaxed the rules on her as well, and she spurted ahead to beat me out. I have always been competitive, and losing in this way was quite devastating. This was compounded by the congratulations that my classmate received, which only seemed to rub in my own personal failure. I know that this was not their intent, but nevertheless, in our society where “winning is everything,” this was the net effect.

There is no doubt in my mind that the organizers of these events had our good in mind. Perhaps they anticipated that I was much more mature than I was, and that I could handle this loss. However, the actual result could have been anticipated quite easily. Why would they let me compete with those who had developed their skills to the point of being almost “professionals?” I realize that they bent the rule for me, and they felt like they had to bend rule for her as well. I also realize now that I was a sore loser. But at this point with the vulnerability that I had in just having been confined to my wheelchair, this was devastating.

It was not until late 1970’s that they began to open it up for physical handicaps as well as the mentally handicapped. This was one of the first time that it was open to all in Tuscaloosa. The idea was to have the fun of competing, but many of our society are sold on winning being every-

thing, as was I at this point in my development. The coaches and teachers encouraged all of their students to participate, and in this case there was only one kind of wheelchair race.

I can see where this might be great for kids who have lost their legs and will have to depend on their arms for getting around; but what about MD kids who are destined to lose their arm strength as well? There are two types suited for wheelchair racing – those paralyzed from the waist down and those who have no legs – they will have tremendous upper body strength. It might seem reasonable to have different wheelchair races for each type of disease, but in any event, it would not be fair. Cerebral Palsy, for example (as well as MD) affects people in different ways and there are different types of them. The bottom line is that without training and understanding just what the race was all about, I should not have been included. Perhaps later in life this event was to have a positive aspect, but at this critical point in my fragile deteriorating condition, it was one more downer that I did not need.

*This was my first introduction to the Special Olympics and I participated several times in the future. I will have much to say about the positive aspects of the Special Olympics in due order, and I do not want to give the impression here that I am at all negative to this overall effort. It was just this particular implementation that was ill advised.*

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As spring of 1979 came around, the warmer weather called to me for the first time in my wheelchair. Our house was built on top of a hill, and it was quite difficult for me to get around outside. I found this quite constraining and inconsistent with my previous spring experiences. Perhaps this was one fore-runner of a second bout of depression that I had in May. This was a much longer and much rougher period than the first one.

One of the problems, I believe, was that I never really internalized the fact that: “I am in a wheelchair, I have Muscular Dystrophy, and I will never walk again.” It just never entered my mind at the time. I am not sure if I was just putting off thinking about it, or if I had hope that this was just a temporary problem – something from which I would recover. I now believe that if I had faced up to this it would have been something that would have caused a grieving period to get through, but once I had internalized it, I could have dealt with it more effectively. As it was, it seemed as though I had some need to feel guilty about something. Not being a psychiatrist, I do not know how to describe this. I recall going through a spell of being afraid that I was lying to people. For example, if someone came up to me and asked me what the color of the car was that just passed by, and I said that it was red, then later on I would get to thinking that maybe it was blue and that I should confess this to them. This seems so trivial and stupid at this point, but it gave me considerable guilt feelings at the time. When people would ask me how I was doing and I was going through some physical problem, I did not know whether I was to say “just fine” or to actually elaborate on the problem (which I know neither they nor I wanted to hear). Usually I would just say fine, which I can rationalize just fine today, but when I was younger this was a real problem for me.

Similarly, when I had a problem with my schoolwork and the teacher would give an explanation and ask: “Do you understand?” I would tend to be afraid to answer yes or no; so I would just respond: “If you say so.” This, of course, would not go over too well with the teacher. My father

explained to me just how ridiculous I was being, and that put an end to my feeling guilty. He explained to me that unless I was intentionally trying to deceive and mislead that I was not lying. Just making a mistake is not a lie. On the other hand, it is even possible to tell a lie when the literal meaning of your words are the truth but the intention is to deceive. We see this a lot with our politicians.

The point in all of this is that there are several major factors coming together at the same time. There is the possibility of a chemical imbalance causing the depression. There is also the moral aspect – recognition of my responsibilities to society and to God, and that I will be held accountable to both. The depression was caused far more over a feeling of guilt than a loss of physical capabilities. However, the loss of my physical capabilities was certainly instrumental in causing these feelings of guilt because I was unjustly blaming these problems on others, most specifically my parents.

In the spring of 1979 this need to feel guilty surfaced once again and grew even worse. It started on a Tuesday when I was going along with my mother on a walk (with me in my wheelchair) through the neighborhood. Suddenly, I began thinking ugly and mean thoughts about my parents (especially my mother). I soon began wondering if I loved my mother. I could not stop thinking that this must be impossible while harboring such evil thoughts. I realize in hindsight that random things like this pop into people's heads all the time and are quickly squelched. However, at the time I took each one of them to be a proof of my own sinful nature. I felt like I was carrying the burdens of the world.

There seemed to be a need to find someone that I could confess too just so that they could tell me that it was all right. I finally got up the courage to tell my mother what kept popping into my mind. This was a mistake, since she did not take this very well and began to get upset. So now there was a dual problem. Not only did I have guilt from thinking these things, but now I had guilt for causing her emotional pain. This, of course, was not her fault; she was not prepared for me to state that I was fighting the thought to blame her for my woes. All I can recommend to parents is that they not take what their children say personally when they are trying to work through these things. If you get personally involved you lose your objectivity, and there is no way that anything positive can come from these confessions. Confessions have to be accepted objectively, not emotionally. However, this is all but impossible when the person you are blaming is the one to whom you are confessing. Of necessity they receive it as an accusation, not as a confession. Confessions of this type should be made to those who can remain objective about it and come back with assurance and advice as opposed to denial.

This incident initiated what might be called a guilt trip – in reality, a deep depression. When I went to school the next morning I was carrying a heavy burden on my shoulders. On my first bout with depression, school had been a remedy. It distracted me and snapped me out of it. This time the school year was nearly over, and perhaps it was the fact that it had worn on so long that added to the problem. In any event, school seemed to be as much of a complicating factor as it had previously been help. Finally, around mid-afternoon of that school day I could not keep my emotions in check any longer and I broke down in tears. Of course, this came as a complete surprise to my teachers who saw no reason to trigger such behavior. It is rare for kids to cry about

things that have accumulated over time and culminated the night before. It is easy to understand how they could have thought that I was emotionally disturbed. I had trouble explaining it to myself, much less anyone else. They even brought in a school counselor to try to see what the problem was. She thought that I felt guilt over cheating on a test or something like that. I remember thinking: "If only it were that simple."

When school let out I went back home. I talked to Mom about it again, and found that the problem was not as severe as I thought. I expected her to still be upset, but when she came to get me at the bus she spoke kindly to the bus driver. I apologized for what I said and she accepted. In hindsight I can see why there was a misunderstanding. Apparently she thought that I brought it up to hurt her feelings. In reality I could contain myself no longer because of my guilt feelings. I wanted her to say something to remove the guilt. But this is difficult when the reason for my guilt was that I was (unjustly) blaming the one to whom I was confessing. Her positive attitude certainly helped me on this day. Could it solve the problem of my depression?

Unfortunately, this was not to be the case, and this first round was only the beginning. I could not control the negative thoughts about my parents that would continue to come into my head. Soon I would have the same thoughts about my father. Sometimes I would sit around the house aimlessly watching TV, and other times I would sit in a trance; but I was so obsessed with these thoughts that I just could not clear them from my mind. I was hoping that I could just confess this to someone, and that they would say that this is natural and that it was something that I would get over. But after the conversation that I had with my mother on that Tuesday night, I did not feel that there was anyone who I could confide in without causing more problems than this could possibly solve.

In retrospect, I recognize now that what I was hoping for would probably have not given me any relief. Because, even when Mom and I reached a resolution of the matter, it did not stop the negative thoughts that I had. Instead, my depression got deeper and deeper, to the point that I stopped eating. My father began to have to threaten me to finish my meals. I would spend hours apparently watching TV, but not really knowing what was even on. This was a mistake, for when these thoughts came into my mind, this just gave me opportunity to dwell on them.

At school some of the worst times of the depression came during shop class. For whatever reason, we hardly accomplished anything. It was mostly dead time that gave me additional opportunity for my mind to dwell on these thoughts. In contrast, our home economics class always had activities and this tended to keep my mind off of it.

The depression got so bad that there were some times that I did not even feel like going to school. I missed several days of school on account of this, and the time at home had no distractions, which let to a vicious spiral.

When I did not feel like eating I would fall back on the excuse that my stomach was bothering me (I rationalized that it was, but for depression and not for physical reasons). At other times I would make up that I had stomach pains. I did not realize that they were taking this seriously until they took me to a doctor specifically for this. The doctor gave me something to drink that tasted

like melted down chalk (I know that there is no such thing, but imagine if there were). If I did not have stomach problems before, I did now. I did not feel that I was intentionally being deceptive – I did not know about emotional distress and felt that maybe there was a problem. The doctor stated that there was nothing physically wrong with me and advised that I get counseling.

I would not open up to the counselor at school, so my parents made me an appointment with a psychiatrist. My impression at this age, based on what I had seen on TV and heard from my friends, was that you should not go to a psychiatrist. I had the idea that they would tell me something like: you really hate your parents or something like that. Of course, this is not what I wanted to hear. However, with all of these evil things that I was thinking about my parents, I already had the idea that I probably did not like them. But, I sure did not want anyone to discover this or to say it out loud to me.

So when I visited the psychiatrist and he began asking questions, I just clamed up. Needless to say, we did not get much accomplished, and that was my first and final visit to the man. I wonder if he did not think I was really disturbed; and yet, he could tell I was not crazy from the guarded way that I approached our interview. I asked my parents what he had told them, and they said that the only thing was that I refused to talk to him. There were no conclusions of diagnosis. His major thought was that I could not be helped if I did not want to be helped. In hindsight I wonder if I could not have gotten over my depression quicker had I opened up to him. I am not sure, but then there are some things we just have to work out for ourselves.

My parents were very sympathetic with me. They were always trying to take my mind off my problems and to get me interested in something. The teachers at school are also to be commended since they were trained quite well to handle this type of depression. However, despite their efforts, the depression persisted, not just as school let out for the summer (as in the previous year), but for all summer long.

Subsequent discussions with my mother, years later as I prepared to write this chapter, the only thing that I can now attribute this to is that somewhere in my subconscious I blamed my parents, and especially my mother, for my having MD. For some reason in my immature mind, this was my way at striking back. To this day, however, I am not convinced that this was the reason; this might just have been a symptom of the shock of internalizing my worsening condition. I know that consciously I was not trying to strike back at her for anything; I could rationalize that she had no control over this, and that it could not in any way be considered her fault. The alternative at this point would seem to be to take the blame myself. It was not until later that I would mature to the point of being able to recognize that this was not the fault of anyone, and that there was a positive purpose for everything.

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All was not a total loss in the summer of 1979. While the positive memories were few, they were significant. For one thing there was MDA camp. The depressions and the thoughts that seemed uncontrollable were confusing both to my parents and me. My mother began talking to the school counselor who suggested that I should be with friends my own age who were suffering from

the same effects that I was. It was then that we decided together (at least it appeared this way to me) that I should spend a week at MDA Camp near Wetumka, just outside of Montgomery.

Just getting to the camp was an adventure within itself; for it was about this time that the truckers within Alabama went on strike, which greatly threatened the gasoline supply. Thus, there was the possibility that the camp would have to be called off, since no one would be able to get to it. Some truckers were going against the strike and delivering their gasoline. However, some snipers were shooting at these trucks, and there was a general reluctance of most people at this time to get out on the highway. However, before the situation developed into a complete crisis, the state troopers began escorting gas trucks to their destinations, and generally, fuel was available.

As we started on our 2-½ hour trip to Wetumka, we stopped at a Dairy Queen to pick up some hamburgers to eat on the way. Mom had told one of the workers where we were going and that we were afraid that we would not be able to find anyone still selling gas. It turned out that he was from the area and gave us directions to an out-of-the-way station that did not have many customers so would probably still have a supply of gas. While I was certainly against the violence that was threatened, I must admit to some excitement in observing the state troopers escorting the gasoline trucks.

The week in June that I spend in the MDA camp was a lot of fun. Meeting people my age with the same problems as I had tended to distract me temporarily from my depression. They had a number of activities planned, from morning until evening, so we really did not have a lot of time to ourselves. Occasionally there were some lapses when I would slip into depression, but for the most part that week was an oasis in a desert that spanned the entire summer. Strangely, I did have a case of homesickness that I felt around the middle of the week. This would have been inexplicable if I had really felt the problem to be home based. However, in the broader context of dealing with and internalizing my situation, it was quite explicable that I would long for those who supported me most. One of the counselors at the camp allowed me to call home. Finding that everything was normal and OK at home was sufficient to put down this feeling and restore me to an attitude in which I could enjoy the activities at the camp for the rest of the week.

It could be that some of the more miserable aspects of the camp served to distract me from my deteriorating condition. There were two things that I most disliked about this particular camp. First, you had to get up so early in the morning – around 6:00 AM. What made it worst was that there was another camp just across the street from us which had some type of para-military outfit, probably a high school ROTC group, and they began their day at 6:00 AM with the sound of reveille. This woke up most members of the MDA camp, including myself, if we were not up already. It would not be nearly as bad if we would have had an extra half hour or so to wake up. But they treated us about the same as the ROTC group, and I could not figure out why we had to get up so early. Surely most of us were not used to getting up at this time. The other thing that bugged me was that we did not have air conditioning in our cabins, and Alabama in June is just too hot for this. Again, there were very few of us who did not have air conditioning in our homes, so this tended to make for considerable complaining. To compound this problem, the mosquitoes easily got into the cabins at night, and fed upon us to their hearts' content. I went home with quite a collection of welts. Since there were not many of them, the girls got to stay in one section next to the lounge,

which was air-conditioned. So, this gave us a lot to complain about, which might have had some psychological advantages. I would hate to think that the camp was intentionally making life miserable for us just to get our minds off of our other physical problems.

The activities in the evenings, right after we finished dinner, were the most fun. One night was declared to be talent night, and all of the campers took turns performing the talents with which they had been blessed. A couple of them sang, and some told jokes, and one played a flute. The funniest night was the Las Vegas night, where they had all kinds of fake gambling devices and paraphernalia in the hall. All of the campers went around “gambling” with fake money. Those who lost all of their money went to the section that they called the poorhouse. In most cases, however, the counselors would just stake the person to some more “money,” and they would be back at it again. You could win real prizes; for example, one of the prizes that I won was a football.

One of the activities that should have been fun for me was not very pleasant – swimming. There was a lake by the camp and every day we all spent some time in the water. The problem was that whether you could swim or not, everyone had to wear a lifejacket. That was bad enough; but the part of the lake that we were “swimming” in was so shallow that if I stood up at least half of me would be out of the water. So, the only thing that I could do was to float on my back, which soon became quite boring. I could move my hands and arms, so I could move around all right, but constantly looking up got to be quite tedious. Later on I paid for it with an ear infection, since lying back in the water like that was an open invitation for water to get into your ears.

Every afternoon they had a rest period. I was afraid when I saw this on the schedule that we were going to have to take a nap. However, it turned out to be just a free time when we could take a break, sit around and talk, which was a lot of fun. One event that seems funny now, but at the time was quite miserable occurred on our last night there. We left the camp and went to a nearby area where we were to have a picnic to celebrate our last night together. After all of the other activities, I had gotten extremely thirsty. It was getting close to the time for the picnic, so I just thought I would wait and get something there. They loaded us up in vans and other vehicles, and took us to the area. As we got there everyone was unloaded, and I could not wait for some coke or sprite. To my great distress I found that all that they had brought with them was tea. Tea, to me, was one of the most disgusting drinks known to mankind, and here I was dying of thirst with nothing but tea. I voiced my discontent, but they could not go back for one coke, and so I managed to keep a little tea down. When I got back to camp, however, I made a beeline for the coke machine.

Each camper had their own counselor assigned, who would stay with them night and day and take care of whatever need that they might have – going to the restroom or getting dressed, etc. On top of that, there were others there who had no one to whom they were assigned. They floated around to wherever they were needed most. They helped everyone, even the other counselors. My feeling about almost all of the counselors that were there that year was that they should have taken quite a bit more training in sensitivity. One of the common misconceptions of people toward those with MD is that the patient is overweight due to the enlargement of the patient’s stomach. However, the real reason is that the muscle tone is gone. Insensitivity arises when MD patients are subjected to “fat jokes,” which are not jokes at all but rather a bad taste attempt at humor at the expense of helpless victims. On a couple of occasions I heard such comments being made, and that was

some of the nicer things that I heard. For example, one camper was getting dressed with the help of his counselor assistant. He could not hold his leg up, and the counselor told him that he looked like a dog. This might have been acceptable (although barely) at an older age, and perhaps by someone who was more familiar with the personality of the individual. But for someone at this age, and at this stage of their internalizing the problems with which we would be faced for a lifetime, this was nothing short of cruel. It hurt me, and it was not even directed at me.

On top of that, some of the counselors were more immature than the campers, although for the most part they averaged being about 10 years older than most of us. One group of counselors decided that they would participate in a panty raid. Now while most of the campers were male, there were a few of the rare cases of MD girls who were there. Somehow, the people who ran the camp got wind of what was going on and some of the counselors were sent home early because of their involvement in this scheme. My own counselor was under suspicion of being involved, but they allowed him to stay. Perhaps they could not prove that he had a role in it, or maybe it was not a major role. However, one of the counselors lied to him and told him that I was the one that had tipped the camp management off. This was impossible, since, although I had heard the rumor, I did not know who was involved. He at first chose to believe what was stated, but in the end he came around to recognizing that I had nothing to do with it. Of course, this put a strain on our relationship, and caused what otherwise could have been a very positive week to result in additional stress. It did not have a major effect, since there were only one or two days left when this occurred. If it had happened earlier in the week, I probably would have gone home early.

The campers at the MDA camp were at various stages of Muscular Dystrophy. There were some, like myself, who were wheelchair bound, while others could walk without much trouble. Some would soon be confined to wheelchair, although they did not realize it at the time. This presented a problem, not only for them, but for some of the counselors as well.

The group went on a rather extensive field trip and most of the kids my age were in their wheelchairs even though they could get around in a limited way. After we got back one of the kids got thirsty and asked the counselor to push him to the water fountain. Seeing that he had been in the wheelchair most of the day and recognizing the need for exercise, the counselor told the child to get up and walk over to it. He decided that he did not *want* to do that, so he just sat there. There was also another boy there that day in similar health circumstances whose parents had told the counselors that he really needed to do more walking. He was a real problem since he was constantly complaining, even screaming and crying when they would not let him stay in his wheelchair.

This seemed to be a particular problem at this camp, perhaps because of the way that the counselors handled it. Since most of the other kids were confined to wheelchairs, there was a lot of peer pressure for everyone to just stay in their chairs. I am not sure how this could have been avoided, since most of the kids needed to be in wheelchairs most of the time. Perhaps there should have been some separation of those who could exercise and a regular expectation for them to do just that instead of it being something that was just left to the jurisdiction of the counselors.

Overall, my experience with the MD camp was quite memorable and positive. While I had some criticisms of the counselors, I believe that this was more a problem of lack of training and

immaturity than anything else, and at no time did I see any of them mistreat or show animosity toward the campers. It was just that when they were off duty sometimes their childlike mentality got the best of them – and that was only for three of the 30 or 40 counselors that they had at the camp.

I would strongly recommend that parents send their handicapped kids to camps such as the one that I went to. Even though this one was probably not the best-run operation, it was still a very positive experience that helped me cope with a very difficult transition. There might be a question as to what parents should do if the child resists this experience. It is essential to recall that handicapped kids are not any different from other kids in this regard. That is, some will enjoy these types of experiences very much, and others may feel quite threatened by them. Thus, this is an individual thing that should fit the child's personality and needs. That which is resisted one year might be quite welcomed the next. My feeling is that unless there is some strong resistance, parents should go ahead and send them, and I feel that in most cases this will turn into a very positive learning experience, and it will be appreciated.

My cousin Kevin had an interesting experience when he went to camp in Louisiana. He did not get much enjoyment out of it, and as a result, went home after just a few days. He never told me why he left early. I believe that it had to do with his living in a rural area. Perhaps he was already out in the country and so this was nothing new and it was boring. On the other hand, he also had nothing like Oak Hill special school, and because of his disability, most of his time was spent at home. It is quite possible that when he went to camp it was just too much of a change for him and he got home sick.

The incidents related above were of my one and only experience with a summer camp. It was not that we intentionally avoided them in the future. Something always came up – a vacation trip or something else – that got in the way of my going. And then, after several years, I just felt that I was too old for this type of thing. However, I still think back about that experience and wonder what my fellow campers are doing now, and how many of them might still be alive.

While camp diverted my attention from my depression for about a week, once I got back home I resumed my depressed state. It was about mid-summer, and the negative thoughts about my parents were difficult to fight. To this point I had never told my father any of this, for I suspected that since my mother had such a negative reaction (at least as I perceived at that point), then my father would probably react in much the same way. However, there was still a psychological need in the back of my mind to obtain reassurance in order to relieve the guilt.

This time, I feel, was far worse. For, over the weeks that followed it seemed that the evil thoughts about my parents were beginning to transform themselves into evil thoughts and hatred toward God. This was much harder to deal with. To some extent I had managed to deal with my negative attitudes toward my mother by going to her and discussing it with her. And, even though this caused an understandable negative reaction with her, in a very short time we managed to work it out and restore our relationship. But, obviously, I could not talk face to face with God. In my emotional and spiritual immaturity, when these thoughts came into my head, I felt totally incapable of dealing with them in any other way except just to feel guilt.

Having been brought up in a religious environment and attending a very bible-based church on a bi-weekly basis, I had learned much at this point about God and Christ. My negative feelings even extended themselves to Christ at this point, which I found quite alarming. This was quite difficult for me to internalize: thinking mean thoughts about someone who gave his life on the cross for me. I guess that atheists would not have this problem; but I can imagine that they would have a different set of problems that could be far worse.

My guilt began to express itself in terms of concern for my soul and my eternal destiny. I wondered if thinking these evil thoughts was going to keep me from heaven. I now realize that when you sin, in thought or in deed, you need to run toward God and seek forgiveness. However, for the next few years of my life I was to be like Jonah – running away from God and trying to avoid my responsibilities to Him. Of course, I continued to go to church. At 12 years old, I still had no choice in this matter. But during the rest of the week I avoided any references to God. For example, if someone would mention something of a spiritual nature, I would avoid the subject and go on to something else. I realized that I did not have any type of relationship with God, and instead of trying to do something about it, I just avoided the whole issue.

A short time after the MDA camp during the summer of 1979, I attended summer school, as I had the previous year, although at a different location. Some of my friends from all over town were in this class, including some that I had not seen very often since last summer. Jimmy and I resumed our love/hate relationship as we competed for class joker. I was surprised to find that one of the student teachers from last year was a teacher this year. She was the one that had the friendly attitude over which Jimmy and I were always fighting for attention. Now that she was a teacher, she had more of a sense of authority about her that I had not recognized before.

Like the previous summer, every Wednesday we would go to the cut-rate matinee at the movies. At this point I was one of the few in the class that was confined to a wheelchair. Most of the others were not to the point that I was where they could not help themselves in and out of the wheelchair when getting in the cars. As a result, my mother had to come to school on Wednesday to assist me. As someone who valued my maturity and independence, this did not appeal to me at all. While this would not seem to be a great intrusion on my manhood, it was certainly of discomfort to me at this time. This was quite time-consuming for my mother, and I knew that these second-rate movies did not appeal to her. Actually, it got to the point where they did not appeal to me enough to warrant my bothering her and losing my sense of independence. So, in due time, I gave up the trips to the movies and just stayed at home on Wednesdays.

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A most startling event took place in summer school during one of our swimming outings. The pool that had not yet been completed when we moved in the previous spring was now ready to be used, and we would go swimming about once a week. There were a few men there who would help me get dressed into my swimming suit. About two or three days before going swimming for the first time I was quite nervous wondering if I could stand up in the water, since I could not stand up on my own. I mentioned this concern to my mother, and she stated that I had nothing to worry about; that gravity was quite different and the water would give me support. So, I was quite excited as the time drew near.

My excitement was short lived, as I found that everyone, regardless of condition or swimming ability, had to wear a life jacket. This was the rule, since none of the teachers there were certified lifeguards. This seemingly minor inconvenience was a major blow to my morale. Here was one of the few physical things that I could do, since I had always been a good swimmer. And now, I was not even going to be able to see if I could stand up or not. This went on weekly for about a month or two, and it drove me crazy not being able to test to see if my buoyancy would counter my lack of balance and agility. But, what could I do?

One day when the teacher was in the pool, a number of the students were ready to get out after our session was over. About five or six were lined up in a row getting their lifejackets taken off, and the teacher had her back to me. So, I waded back into the pool away from the edge and, seeing that she was not looking, I quickly removed the lifejacket. It felt like a piano had been lifted off of my back. I was free, and for a split second I recaptured the essence of physical freedom that can only be fully realized by a healthy pair of legs. What Mom had told me was true: the water took the weight off of my legs and also provided the resistance that enabled me to easily maintain my balance. I felt cured ... free at last ... I could move around ... was this a dream? Yes. Quickly I was back to reality as the teacher scolded me for taking my lifejacket off prematurely. However, this was of little consequence. I learned that I had the ability to get around in the water, just as my mother had said. The teacher's words went right through me without having any impact at all; I was in another world ... a world of freedom, if only for a short time, and I was going to enjoy every second of it. Her words had not the power to sway me the least bit. No consequences that she could impose could possibly matter.

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The spells of depression came and went throughout the rest of the summer. It seemed to get better toward the end of August after summer school was out when we took our annual trip to Louisiana. We would usually go to Fort Walton Beach, a beautiful city on the Gulf coast at this time; however, being confined to a wheelchair made that trip nearly impossible, and so we went to Louisiana instead. Visiting with my grandparents and cousin, I was kept busy and did not have much time to contemplate all of the ramifications of my condition.

The depression would have started in again, I am sure, when I arrived home. However, within a couple of days of getting back I began the seventh grade and with that the depression seemed to evaporate quickly. With the exception of a couple of weeks in 1980, the depression seemed to have gone for good. To what do I attribute this turn for the better? In subsequent chapters I will address this in greater detail. In this case I believe that the support that I had from my family and friends was sufficient to get me through these bouts with depression. Once you get through one then you know that it is not the end of the world, and you know that you can overcome it. However, the benefits of counseling and, when warranted, medication, should not be minimized. Each individual case is different.