

## CHAPTER 4

### FIRST YEARS OF SPECIAL ED

(Ages 8-11 Years)

September, 1975 represented a major turning point in my battle with MD. Two months away from my 9th birthday, my parents informed me that I would have to begin attending special education. This was not due to any significant deterioration in my condition. It was more a decision that was made by my parents based on my mental attitude. They had noticed that while I was performing well with regard to reading, math and other academic subjects, I was falling behind in physical education and was not able to keep up with the other kids. They felt that this might start to deteriorate the generally positive attitude that was able to sustain me to this point. At this age the physical aspects of competition are crucial to one's self esteem, especially for a young man. Perhaps some never grow out of this; but for those who are losing, rather than gaining, in physical abilities, growing out of it is a necessity. I do not recall this being traumatic for me personally, and I believe that I could have gone to the regular public schools for another year or two without too many problems. However, their concern was probably well justified based on what is typical of MD children. Also, there were only one or two schools in the city that offered special education, and there was a waiting list. My parents wanted to play it safe to get me into the school at least the following year, but there was an opening, so they accepted me during the first year.

Mom and Dad put the best possible spin on the situation when they broke the news that I would be attending a different school. For one thing, the number of students would be much smaller than at the other school, and the teacher would be much more available to help me if I had any problems. There was also the knowledge that the other children there had problems similar to mine. (At first their problems were much more severe than were mine, and so there was an immediate role reversal, which I did not mind at all.) Finally, there was the fact that the facility was much newer than the regular school, with carpeted classrooms and central air conditioning. While this was no big deal for a kid my age, the fact that my parents hyped these factors up alone made it seem something special. I will say, however, that the air conditioning, especially during the spring in Alabama, was a major plus.

Starting special ed affects different kids in different ways. Some kids have problems with this due to their backgrounds and personalities. My feeling, however, is that this is the exception rather than the rule. Parents whose children are born with handicaps know from the start that they are going to need special attention, and there is no real problem in their getting accustomed to it. However, the relatively slow onset of MD makes it problematic as to the exact point to abandon the attempts at normal schooling in favor of special ed. I feel that the decision made by my parents in this regard was about optimal. True, they could have gone another year longer, but at least they were not so overprotective as to pull me out before the third grade.

It is quite important to recognize that this decision is a critical one, since it is the juncture where the child can no longer identify with normalcy. What seemed like a long way off – something that might never be – is now reality. Theoretically, the ideal would be to put this off as long as possible. However, the real question is: will the child suffer more from being subjected

to the expected abusive behavior of the “normal” kids or from being placed with kids with disabilities. Certainly, there is no magic age for MD children, and I do not wish to suggest one here. However, it is my firm belief that parents should recognize that the day *would* come, and they should consider all of the factors that can impact the child’s happiness before solidifying the decision. If I had to err, I believe it should probably be to spend an extra year with the normal kids, but this should be determined by close observation of not only the child’s interaction with normal children, but also his/her reaction to other children with similar disabilities. This is another reason for promoting exposure with children of disabilities prior to this critical juncture.

The primary physical problem I was having was an upset in my sense of balance. This was causing me to sustain injuries, especially on the playground. It began to manifest itself in small injuries and bruises at first, which were difficult to distinguish from those which most normal kids pick up from time to time. Parents need to watch closely for this change. Sometimes teachers can detect the onset of this problem, since they have the other children for a control group. However, with all of their other tasks, it is generally too much to expect the average teacher to spend the time and efforts required to keep track of such things, and this is another reason that the timing of the move to a special education class is so important.

More importantly for the MD child is the advantages of their association with other handicapped children who have either dealt with their limitations all of their lives or else who have learned to deal with them. This tends to make the transition to a wheelchair much easier to handle both from the physical and psychological points of view. At this point the MD child might not be willing to even entertain the idea, since they are still in a semi-state of denial. For example, it is important that handicapped children learn the appropriate ways to seek and obtain help. They must first learn to cope with the fact that it is all right to attempt a task and fail. They need to be able to say to the world: “It’s all right. I have done my best to do this. Now I need help to accomplish it.”

There is a subtle dividing line on the tightrope balancing self-sufficiency and the solicitation of help from others. This is something that parents are often ill equipped to define because of their closeness to the situation. They might have a tendency to push their children beyond their physical or psychological limits; or, alternatively, they might understate their capabilities and end up doing everything for them. Either extreme can be harmful, especially as physical capabilities are being lost. In essence, the tightrope itself is moving.

My special ed class at Northington Elementary consisted of 10 students. We were fortunate to have enough space where we could have desks in one room and an open area for activities in another. The special education was in a separate wing at the normal school facility. It included those with learning disabilities, those severely retarded, and those with a wide variety of physical disabilities. These were divided into separate rooms, so I was in the room with those with physical disabilities. The classrooms, however, were not divided by grades, so year after year we would have the same classmates and often the same teacher. This had the positive effect of allowing many close relationships to develop between the students.

The teacher that I had for third and fourth grades was very nice; she seemed to consider us her own children. She and her husband had a house on the shores of Lake Tuscaloosa, and one Friday afternoon she had all of us over for a picnic. This was the first of many such parties,

and even after school was out in the summer she had us over for picnics. She was indeed a dedicated and loving person, and it is hard for me to imagine what life would have been like had she been very authoritarian and dictatorial. Parents need to be aware of the interactions between their children and their teachers as this critical point to determine the relationship that is developing between them. This is crucial since the transition out of what most people consider to be the normal child society can be a very traumatic one if both parents and teachers do not handle it properly.

It should be emphasized that the most important requirement for a special education teacher is the ability to teach. Many of the children who go through special education will never have their physical abilities to fall back on – if they are going to become self-sufficient it will be by what they know. Teaching ability for handicapped kids goes far beyond the mere presentation of knowledge. The most critical aspect of teaching is the ability to motivate, which is not significantly different from teaching in general. However, motivating a broad range of handicapped children simultaneously introduces an added dimension, increasing the challenge. A major problem is that children who might be slow learners due to their handicaps are placed in the same class with some who are extremely bright. Similarly, just because a given individual cannot perform one physical activity does not mean that this same person might not excel in others.

The difficult decisions as to when to initiate special education (and all others that involve physical and intellectual expectations) are best made if they totally involve the parents, the teachers and the child. The parents have the most experience as far as the history of the child is concerned, while the teachers can bring a degree of objectivity that is just not possible for normal parents to have. (This is not a criticism of the parents; indeed, the special love that they have for the child sometimes gets in the way. This same love should motivate them to seek more objective guidance from teachers as they do from medical doctors.) The child is the third critical component of this decision-making process. If there is a strong desire to continue in the normal school this should certainly enter into the decision, although it should not totally control it. On the other hand, if the child is not having the best of experiences with his/her normal counterparts, then the move to special ed should be accelerated.

With regard to child involvement, parents often overlook the extent to which their handicapped children take advantage of their handicap to get what they want. They should not be faulted for this, since this again is a characteristic of all children, and handicapped kids should not be expected to be immune from it. Parents are at fault for allowing this to get out of hand. However, even parents of normal children have a problem with practicing the type of tough love necessary to keep this under control. It gets trickier with handicapped children in that they tend to have an “excuse” for their wishing to take advantage of the situation.

Some handicapped students will intentionally do things to defy authority in order to elicit the acceptance of their peers. This is analogous to the “naughty preacher’s daughter syndrome.” It is a cheap way of getting attention that is difficult to otherwise attain. I can recall one handicapped student who was going to the regular school who suffered from epilepsy. He occasionally would have seizures at school, and he would take some of his medication that had a sick effect of swelling up his gums, making him look quite afflicted. His personality did not quite jibe with the accepted norm, and so there was a tendency for him to be persecuted over these anomalies by some of his peer group. To prove his man-hood, he would inevitably challenge them to a fight.

So, he spent most of his time in the principal's office. Finally, they decided to remove him from the regular school and place him in special education, where everyone else had their own problems as well. Whether this worked or not is problematic. My impression was that he was just plain mean to begin with, since, rather than sympathizing with those who had problems that he should be able to relate to, he would take advantage of those problems to exalt himself. Handicapped people are just like others – you can expect the normal proportion of them to just be plain nasty. They would be this way with or without their handicaps.

However, it should be expected that some handicapped kids would misbehave in order to get attention (and perhaps peer acceptance) that they cannot otherwise get. For example, my cousin Kevin was the only one at his school who was totally confined to a wheelchair. Although I cannot recall him saying it in so many words, he implied from what he said, and certainly by what he did, that he got himself in trouble many times for no other reason than to gain acceptance from his friends. My impression after knowing him for a few years was that this was a temporary stage and that he quickly outgrew this problem. I cite this not as something which is unique to the handicapped. I am sure that many “normal” kids go through the same problems for lack of attention, either at home or among their respective peer groups. However, because handicapped kids generally do not have the same outlets to excel physically and gain acceptance in this way, this problem could be accentuated in some of them.

To counter this, handicapped children should be encouraged to push their physical capabilities in a friendly environment in which there is no penalty for failure. Indeed, there might even be rewards for making a valiant attempt and failing. Failing cannot be considered humiliating – it must be seen as a demonstration of courage. Normal children cannot be expected to provide this environment, at least not in the state of enlightenment that our society currently finds itself. However, in the context of special education a mutually supportive peer group can be established. (I am, of course speaking in retrospect now; the changes that occurred in my own attitude with regard to “winning” will be illustrated in the next few chapters.)

Of course, we dare not minimize the downside of isolation. There is a real problem introduced by taking handicapped children out of the normal school environment and placing them in one in which they cannot interact as effectively with normal children. Reality dictates that if the majority of handicapped children are going to lead productive lives, they will need to do so within the context of “normal” society. How is this dilemma resolved? In several ways: First, by recognizing that the “isolation” is not total – children in special education classes should be given as much contact with the outside world as possible. Second, by recognizing that the separation is a temporary incubation in recognition that they will not be in as hostile an environment once their normal peer group reaches adulthood. (The education of the adult population as to the needs and desires of the handicapped is still somewhat questionable, but we will defer dealing with this until future chapters.)

On the positive side, the main thing that I liked about the special education class was that the environment was not as regimented; it was much more flexible. For example we did not have nearly as much pressure to get our work done by a certain time. Often our classes were more like social gatherings than the normal school environment, with some schoolwork thrown in just to keep things from getting too boring.

My mother prepared me for the first time that I was to attend school with other handicapped children. She advised me that some of these kids were going to be in wheelchairs and warned me to be sensitive to this so that I would not hurt their feelings. This is probably a good thing for parents to do – it is a fallacy to think that just because a person is handicapped, s/he does not have the capacity to hurt the feelings of others who are worse off. In my case I did not really relate to this advice, since I always viewed wheelchairs as fun toys. I enjoyed being able to push the ones in wheelchairs around the school building – to the library, to lunch, and outside on the school ground.

A typical day in special ed would start off with a “home room” session in which the teacher would gather us around and give us a general outline of what we were doing that day. After that we would separate into smaller groups and, about half of the time, we would work individually. Group and individual projects and assignments were based on where each student was academically. The subjects covered were essentially the same – reading, math, etc. – as those in the public schools. However, the specific levels varied quite widely because of the disparity in intellectual abilities of the students. In fact, there were some students in our class who had mental disabilities, so they had to be given work at a very elementary level.

One of the first things that we studied in the special ed class was the election -- Gerald Ford and Jimmy Carter. At the time I found this to be extremely boring, but this had nothing to do with special ed – this stuff is boring to all kids. However, this early memory demonstrates that we were probably not covering things that were much different from the other kids.

We also studied about the bicentennial celebration in the Spring of 1976. This tended to be quite a bit more interesting. However, we got somewhat distracted as our class put on a play in which we had to dress up as various early Americans. We told who we were supposed to be and gave a brief statement as to what it was that made them famous Americans – George Washington, Betsy Ross, Dolly Madison, Daniel Boone, and several others. I was chosen to play Abraham Lincoln, and my mother made a coat and vest that I wore along with a long stovepipe hat. It was quite a bit of fun getting to dress up an act like a past character, and I enjoyed playing the part of old Abe, even if he was dead. However, I was quite self-conscious about getting dressed up, especially since this was not something that the normal kids were doing.

I guess these types of things serve a purpose in giving children a sense of responsibility in putting on a show. However, it was not without its downside. The thing that I hated the most was the beard that was “drawn” on me with my mother’s eyebrow pencil. As my father took me to school I can still remember crouching down in the car to let some of the other students go by before I got out. Then I ran straight to the back door and right into the classroom. The teachers kept threatening to march us all over the school for an exhibit that I would have found rather embarrassing. There is a balance between fun and self-consciousness that teachers should be cognizant of when they make decisions such as this. These things should be fun (as on Halloween), not ordeals. There is need for recitation; but it should be done in a way to minimize the potential embarrassment to the children, and this will assure that they get the maximum utility from it.

Looking back after 20 years I now realize that two of my best friends at that time were children that could walk and were able to get around quite easily. Of course, at this time, I was able to get around fairly easily myself. I can trace the process at this point and recognize that as I

became wheel chair bound, so my best friends also were similarly confined. I am not sure if this was a hidden prejudice on my part or just something that had something to do with the personalities involved. It could be just coincidence, and, if not, I do not suppose that this attribute would necessarily apply to everyone. However, the natural affinity toward those who share our characteristics cannot be denied.

I will call my two best friends over this time period Bart and Thomas. Bart had Downs Syndrome and Thomas had a combination of visual and hearing problems. The main reason that I see that we shared such a close relationship was that we all competed for the honor of being the class clowns. Whenever there was trouble in the classroom, one of us was usually to blame. Nothing major, 'mind you, just enough to keep the teacher on the edge of pulling her hair out. Bart and Thomas lived close enough that we would take turns spending time at each other's houses, which was a tremendous source of companionship in this period of transition.

While Bart and Thomas were closest to me, I also spent plenty of time with the kids in wheelchairs, and we developed very good relationships. I recall Pam, who had a slight case of cerebral palsy, since she was always very talkative. Also, there was Sherri, who had a very severe case of cerebral palsy that affected her speech (and just about everything else). She communicated through a very laborious process from a board that contained the alphabet. Nevertheless, she was always smiling and this brought a great amount of joy to all of us. A third student with cerebral palsy, who I will call Doug, was not nearly as disabled, being able to get around with a walker. Another student that I remember in particular, Les, had Spina Bifida, and had to get around on crutches. He was distinctive for his great sense of humor. My feeling was that we would have really developed into great friends had he stayed; however, his father transferred to Huntsville, Alabama shortly after we began third grade.

Some kids resent being placed in special education. I can recall one in the fourth grade who had visual problems for some time before coming over to the special ed class. After just a few months he complained that he liked it much better in the regular school, and soon after that they transferred him back. My own feelings toward our special class were never negative. As far as the work was concerned, there was not that much difference. However, because of the smaller class, it was possible to make closer friends of the students in the special class. Our class never numbered more than about ten, so we got to know each other quite well. This was also an advantage in that it gave the teachers a chance to get to know the strengths and weaknesses of each of the students – information that is essential in handling the emotional needs of such a diverse group. I liked the special attention that we got when we had specific problems with a subject and the teacher could work right with us until we got the problem resolved.

Since our special ed class was held in the normal public school, we were not isolated from the other kids. There were times when we would go and sit in on their classes, like, for example, when they had their social studies sessions. This too was quite enjoyable to me in that it gave me a continued association with some of the kids that I had grown up with to that point. However, I know that the kids in my special ed class were my first love, since when I was offered the opportunity in the fourth grade to rejoin the other class, I rejected it and decided to stay with the smaller class. I guess more than anything else (recognizing a third or fourth graders perspective), the reason that I wanted to stay with the smaller class is that I felt that if I left them I would miss out on some of the fun. While this might not have been valid, the point is that I viewed the

special ed class as *special*, not as part of a dreaded set of outcasts. This, I believe to be the key to making and keeping the kids in special ed from feeling inferior and discontented at this early age – there has to be fun associated with it. This can be accomplished with such things as field trips and special games (especially with the current computer opportunities); but the real key to *keeping* things fun and friendly lies with a caring teacher. And, since I had such a teacher, special education did not have any downside for me, at least from the perspective of a third and fourth grader.

An additional positive aspect was that special ed helped me focus on my condition. During the early days of special ed I realized that there were many there who had names for the conditions that they had, whether it was Down's Syndrome, Cerebral Palsy, or Spina Bifida. At this point, as I have mentioned before, all I really knew about my condition was that I had weak muscles, and this had seemed quite reasonable. But I remember one day after I was in special ed, the teacher sent me over to take a message to the therapist that I noticed that there was a student there who had a severe mental handicap and just seemed to be aimlessly walking up and down the steps. I asked the therapist whether there was any particular reason why she was doing that, and he told me that she had *weak muscles* and this exercise was to make them stronger.

As you can imagine, the *weak muscles* explanation triggered all kinds of reactions within me. I suddenly got to wonder: Did she have the same thing that I had? That is when I realized that I did not even know the name of the condition that I had. So, that night after school I asked my parents about it. They were still somewhat reluctant to tell me for some reason. However, I guess they discussed it that night, for I remember that the following morning right after finishing breakfast that my mother told me that I had Muscular Dystrophy. I don't know what she thought my reaction was going to be – after all, I had to learn the name of it sometime. I guess she was prepared for me to bombard her with a whole series of questions. However, the world is much more simplistic from the point of view of a child, and my only question that I had was: Does this mean that I have the same thing that the girl who was walking up and down the steps has? She assured me that this was not the case, and this was sufficient to deter my concern at this point. As long as my fate was something other than endlessly and aimlessly walking up and down a set of steps, life could not be all that bad.

It was also during my third grade that I began to experience what it was going to be like when confined to a wheelchair. With advice from the doctor, my parents decided that it would be best for me to use a wheelchair when it was necessary for me to otherwise be walking long distances. That would enable me to save my muscle strength for use once I arrived at the target destination. The first device that my parents got to assist me was not like a wheelchair at all – it was like a huge stroller. I sort of enjoyed it at first, but it did not take me very long before it became the object of my hatred. The wheels were so low to the ground that you could not push yourself without falling out of the thing. This resulted in my being stuck wherever I was stuck. Quite often, for example, in the mall they would leave me to run off to check something, and I had no recourse but to count the number of tiles on the floor.

Despite this, the use of this “wheelchair” was not nearly as traumatic as what might be imagined. Perhaps because I did not feel that it was really essential, I was like a young person enjoying the ride – like any child this age who did not really *have* to be so confined.

Whenever we would go on field trips at school the school would always have an extra wheelchair that I would generally use. I kind of enjoyed it. Most of the other special ed kids were already in wheelchairs, and so there was certainly no stigma associated with it. In fact, I tended to identify even closer with the group when using the wheelchair. I see this as one of the major advantages of special ed during these transition years. Having peers who were more advanced in their disabilities did not create fear of the future in me. Perhaps this is because the “future” is perceived to be far more in the distance to a child than to adults. It is difficult, sometimes, for older people to recall this perception. In my case the peer pressure worked to my advantage in bringing satisfaction in transitioning me into my wheelchair years.

One field trip that we took was to the state fair when it came to Tuscaloosa. They had given all of the students at our school the opportunity to visit the various exhibits before the fair itself was opened for business. I spent most of the time at the fair in the wheelchair with someone pushing me. We went in the afternoon and took the grand tour, after which we all began heading for the school bus. It was at this point that I decided that I had spent more than enough time in the wheelchair, and since the teacher had no big problem with this, I got up and joined Bart and Thomas. We started walking, not really paying too much attention to our surroundings – mostly telling jokes and acting typical third-grade silly. We did not realize how far from the group we had gotten until the teacher had to run us down. She was burning mad. This was one time when I regretted getting out of the wheelchair; perhaps the abuse of the opportunity that I had been afforded made me particularly vulnerable to having a guilty feeling.

The wheelchair is certainly a great aid to children who are fighting MD (or similar degenerative diseases), but it can also be a curse. The major curse is that one is no longer forced to exercise those muscles that are getting weak, at least not as much as before getting wheelchair “relief.” Thus, the partial use of the wheelchair is certainly going to contribute to having to be confined to it earlier than otherwise. However, this is not an either/or decision. There is a point at which MD children just *cannot* keep up, and it does no one a favor to subject them to the embarrassment and distress of surpassing this limit. On the other hand, to deny them the opportunity to determine this point for themselves is also a grave injustice to the child. So, the speed with which the wheelchair is phased in is a delicate optimization problem that should be discussed between child, parent and teacher to assure that the total interests of the child are maximized.

On one occasion when Mom took me to the store she had me in the wheelchair and I expected to be pushed around most of the day. I was surprised when she told me that I needed to get up and walk around a bit. She did not argue that if I did not get up and walk I would be confined to the wheelchair sooner, but somehow this message came through to me, and I realized that this exercise was for my own good. Thus, I never argued with her or Dad whenever they urged me to get up and walk on my own.

Parents should certainly become aware that this is a major issue. Exercise can be quite painful, but this is no different from the many things that children of this age must be persuaded to do for their own good. There is also the issue of balance, and during this period I found it more and more difficult to stand on my own and sustained considerably more falls. This is a further incentive for parents and children to take the “easy way out” and just give in to the wheelchair. While I sustained a few cuts and bruises, I made the necessary adjustments by reducing my risk taking, knowing my limitations. For that reason, I probably had no more injuries than

that sustained my most normal kids (less than some). However, there is a tendency for the parents of MD kids to feel particularly guilty when their kids are injured, as if they should be intervening in all cases to prevent *every* single injury. This just cannot happen, and when parents over-react like this it is quite counterproductive, leading many kids to become wheelchair bound well before this is essential.

I can recall one event in the spring of 1977, during my fourth grade year, when my school got out quite a bit earlier than my sister's school did, so usually my mother would pick me up at school and we would go over to the local food store. I would get something to drink and she would pick up a couple of items, and then we would go on and pick up my sister. The incidental walking that I did in the food store certainly did not warrant a wheelchair at this point. On one occasion, however, there seemed to be something slippery on the floor; for, all of a sudden I lost my balance. I recall it like slow motion, trying my best to do whatever I could to keep from splashing my drink all over the floor. This was what probably caused me to try to break my fall with my knee, causing me to come down in a very awkward position. When I got up with a very sore and bruised knee, neither my mother nor I recognized the extent of the injury that I had sustained.

We helped clean up the mess, after which we picked up Missy and went on home. That night my parents were leaving the house to attend a banquet at the university, and they had a sitter come over. To this point my knee was bothering me somewhat, but the pain was not any more severe than many of my other previous injuries. I figured that it would hinder me for a couple of days, but that it was nothing to worry about. However, later that night as I sat down in a particularly low position my knee would have nothing of being subjected to that extreme, and I recognized that I had more than the typical injury here. Actually, this occurred while I was attempting to use the commode, and as a remedy I went out and secured a stool to put my leg up on in order to successfully complete my mission. Needless to say, the sitter was quite puzzled as to why I needed a stool in the bathroom, but I assured her that all was well, locked the door and took care of business.

I went on to bed around 10 PM, and my parents came home shortly after that. It was not until the next morning around 9 AM when I attempted to get up that I realized that I could not move my leg at all without severe pain. I tried it several times, and figured that I could do it given a little time for it to get over its night stiffness. However, when Mom came in and asked me if I was going to stay in bed all day, I could hide the problem no longer. She looked at the knee and it had become very swollen. We went to the emergency room, which was quite scary for me. I had never been to the emergency room before, and I perceived that there was considerable pain associated with it. However, Mom assured me that since my injury was relatively minor, there would not be any shots, stitches, or any of those things which kids usually associate with pain. Once they did their x-rays they found that I had stretched a ligament in the knee. It was the typical "six-weeks-in-a-cast" type of injury.

The relevance of this event is that quite often MD kids do not get confined to wheelchairs in a continuous evolutionary way. Instead, it occurs in discrete events. This is necessitated by injuries such as that described above, which are practically inevitable. (Recognize again that all normal kids sustain many such injuries.) There is no way that they can be prevented short of complete confinement to a wheelchair, which would be obviously counterproductive at this

point. The problem is that after six weeks of total confinement, the resumption of normal activity at the previous level is practically impossible. However, this particular injury was not too bad, and I did as much exercise as possible under the circumstances, which consisted of someone helping me out of my wheelchair and helping me take a few steps. However, being confined in this way served in two negative ways: it took away the ability to exercise fully, and it conditioned me to becoming immobile. Thus, the knee injury was an ugly harbinger of things to come. However, at this stage I did not view it as such. I had been injured before and recovered fully. And it was fun to acquire so many signatures on my cast. The injury did not keep me from school, since I could put in a full day there despite the cast.

After about six weeks we went back to the doctor to get the cast removed. On the way to his office, Mom cautioned me not to expect to walk as well as I did before I hurt my knee – it would take a while for it to completely heal. While my leg was quite stiff, I did have the ability to walk once they removed the cast. I was a little wobbly, but it was clear that I could walk. In fact, just to prove Mom wrong I insisted on walking out of the doctor's office by myself. As I was hobbling to the car I recall my parents asking again and again if I would not prefer to use the wheelchair. Usually when something like this happens it affects the parents more than it does the child. It appeared, at least to me, that I was back to normal, although I realize now that there were probably some lingering effects of being off my feet for that long from which I would never recover. This virtual full recovery came as a pleasant surprise to my parents. The discrete effect of the injury played on their roles as well, as I cannot recall being allowed to carry my own drink any longer at the grocery store, giving me both hands to catch myself should I fall.

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One of my classmates who arrived in special ed just a month or so after I did was a sweet girl I will call Ginger. Even though she had an obviously disabling case of Spina Biffida, she had a great personality and was always talking. It was obvious that she was not a dull person, and I found our conversations to be quite interesting. She always loved singing and had a beautiful voice. Whenever the opportunity arose for her to sing she would take advantage of it, and if not given the opportunity, she would create her own. For example, when she first arrived in our classroom the teachers could not figure out why she was taking so long in the restroom. When one of them went in to find out, they found her singing in there. Some people only sing in the showers; she sang whenever she got the chance.

As school began to let out for the summer of 1976 and most of the students were talking about what they were going to do during the summer, Ginger stated that she was going to have back surgery. I did not understand too much about it since I was not yet that interested in what the girls were doing. However, the surgery had something to do with her condition, perhaps to strengthen her spine. At the time we just thought that it was minor surgery and did not pay a whole lot of attention to it. I was not aware of the seriousness or the recovery time.

When we went back to school in the fall of 1976 and we started the fourth grade, Ginger was still recovering from her surgery in a hospital in Birmingham. I was almost 10 at this time and was living in a world of my own, just having as much fun as I possibly could. It seems quite cruel to think about at this time, but I did not take her not coming back immediately to be a serious issue. We all felt that in due time she would rejoin us.

It was late September when Mom and I were in the car waiting for Missy to get out of her school. Mom asked me if I were going to hear bad news, would I rather hear it from her or from my teacher. I could not imagine what she was talking about, and wanted to know immediately. So Mom informed me that Ginger had passed away the previous day. Death was always an abstract concept that had little effect on me. Now here it was on my doorstep. My first question was: how did it happen? Somehow the surgery they performed had caused an infection that had spread to her lungs, at which point it proved to be fatal. She had a sister that was five, and I asked Mom how she was taking the news, and she said as good as could be expected. Mom explained to me that her sister being that young probably did not grasp the situation – it was like she was gone on a trip and would return someday. In some ways I felt that this was a blessing; but in other ways it was sad that she would be waiting for an event that would not happen, at least not in this life.

Most of the kids were told the same story by their parents, and our teachers decided that they would not make an announcement about this. Generally these things are handled differently today, but this was their judgment back then. We really did not talk about it for a few months, and then after it got to be a well-known and accepted fact, we talked about it informally among ourselves. There was a great deal of love for Ginger, and everyone loved her cheery singing voice.

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My cousin Kevin continued to blaze the trail for me, since his condition was slightly more advanced than was mine. The first time that I noticed anything significantly different occurred in the summer of 1976, after I had completed third grade when we went back to Louisiana for a visit with our grandparents. My grandfather had his own carpenter shop behind his house, which seemed like it was as long as a football field. Missy and I went to the very back of it and started playing around with his tractor. After a little while we decided to see if the other cousins had arrived yet. Just as we went out and looked toward the front of the shop I saw someone standing there waving at us. It looked like my cousin, but then this person looked considerably larger than I had remembered Kevin. I asked Missy who that was, and she said: “It’s Kevin!” My first thought was that he had sure gotten fat since the last time I had seen him. While we saw each other several times a year it had been some time – probably about four or five months – since I had seen him.

What I did not realize at the time is that usually about a year before an MD patient becomes confined to a wheelchair, the back muscles give way and no longer enable the individual to sit up. The patient becomes sway-backed and awkward, causing the stomach to appear much larger than it really is. This also results in a loss of balance. Fortunately, I had been taught quite well by my parents not to comment on people’s physical appearance, and this certainly averted a potentially embarrassing situation. Years later when I found out that this was part of the progressing symptoms of the disease I felt guilty about even thinking this way, since there I was doing the very same thing and having the very same misperceptions that many people of all ages have regarding MD patients – assuming that the stomach had grown because the patient was just eating too much. While the initial visualization of this struck me, once we started playing things were just like old times, and I did not even notice his new shape.

The day that I learned that Kevin was going to be confined to a wheelchair stands out in my memory, perhaps now because it was not as traumatic as would be expected. I did not know anyone else with MD at this time. When he had the problem with his heels lifting up on him like mine were doing, his doctors recommended that he have surgery to stretch the tendons in his heels. However, this surgery did not seem to accomplish a whole lot, and I assumed that the reason that he had to resign himself to the wheelchair was because the surgery did not go well. And, at other times I just thought that he had a much more severe case of the disease than I did. Whether this was accurate or not, it does show my optimism at the time – I just never internalized that the wheelchair was one day to be my fate.

Fortunately, his being confined to a wheelchair did not affect our relationship to any great extent. We still played the games that we usually played, listened to records, and played with matchbox cars. We even went outside at times and had some great games of cops and robbers. Neither of us wanted to be the robber, so we took turns being the lead cop. So the robbers were all on the invisible side of what exists in the mind of every child. Now, when Kevin became confined to the wheelchair, we did make one little adjustment. At this point Kevin became Ironside (the Raymond Burr character that was quite popular at that time). As you recall, he was confined to a wheelchair. This TV show did much to enhance Kevin's self esteem, and it provided us hours of enjoyment, both watching it and living it out in our childhood diversions.

Soon after becoming confined, Kevin acquired an electric wheelchair, so he was able to go most places where I went. Since he lived right next door to my grandparents, we would visit on a fairly regular basis, and our relationship continued to get closer and stronger as time went on.

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It was about this time that I had to face a few limitations of my own. In the summer after my third grade (1976) our family moved to a larger house on the other side of town, which was practically on the banks of the Black Warrior River. This house was built higher off the ground than our previous one, since it had a crawl space under it. I had to walk up two steps to get to the house, which was becoming harder and harder as time went by. To address this problem my grandfather built a railing so that I would always have a handhold. Later, the following spring when he came to visit he built a ramp from the door to the carport. I did not see these as major turning points at this time; I simply appreciated the ways that my family was accommodating the problems that were growing at such a small rate that to me they were barely perceptible. Some of my fondest recollections include helping my grandfather work on these improvements for me.

The first Christmas that we spent in the new house was not one of my fondest recollections, however. We had come back from Louisiana, and both Missy and I caught the flu that had been going around. So, for the next four days, which was the balance of our vacation, we spent all sick in bed and unable to do much at all. Perhaps this was made up on January 20, 1977 when my sister and I were to experience our first snowfall (a very rare event in Alabama). The reason I recall the date so well is that it was the date that Jimmy Carter was sworn in as President. The teacher had informed my class that we were going to watch the inauguration take place. This was not impressive to me, since, at least to the kid in me, this was mainly going to be a lot of boring speeches. So, when school was canceled on that day, I felt it was a double reprieve. However, keeping my balance on the slippery surfaces caused another set of problems, since at

this point I was beginning to have more than my share of problems even on normal surfaces. But in snow I had an excuse to fall down, and it was not so bad especially since this was the first time in my life that I had the opportunity to build a snowman.

As I started fifth grade in the fall of 1977 there were a number of changes that impacted me. First of all, my best friends had either been transferred to another class or another school. Bart was transferred to another class, and Thomas was transferred to another school where they could help more with his vision problems. We also had a new teacher that year, who had to be the most patient person I have ever met. (Even when she was yelling at you she had a way of sounding nice about it.) She was, however, quite proficient in getting her point across by her persuasiveness and persistence. It was this year that I began to get closer to some of the students who were in wheelchairs. It is difficult for me to tell at this point if this had to do with my other friends leaving or if it was because I was spending more time in the wheelchair myself. I also began riding the bus for the first time. This was not the ordeal that many might imagine – actually we got to socialize with our friends before our workday started, which served several purposes. Since two of my classmates were also on that same bus, this worked out quite nicely, and I think we all enjoyed the time together.

The fifth grade was a pivotal year as far as the deterioration of my condition is concerned. I was going through the same transition that I described for Kevin above. Probably the first thing I noticed, as far as physical limitations, was the inability to get out of the pool when swimming that past summer. It was not long before I could not even do that without help. The situation continued to deteriorate, and soon I had to get the lifeguard to pull me out without even worrying about the ladder. As school started back, my falling down also increased considerably, and it got to be the rule rather than the exception. To avoid such, for example, at home, I would sometimes just crawl from one place to another rather than getting up and walking. My arms also were weakening, and when they would no longer support me, I would crawl on my elbows.

During this time I became quite puzzled as to what was happening. It was difficult for my parents to give me any satisfactory explanations. I did not dwell on this too much, but it was difficult to avoid when I was being confronted with losses of abilities at an accelerating rate. The previous changes had been almost imperceptible. Now it was definitely noticeable. I had ways of coping. For example, Tarzan was popular at that time, so when I would fall I would explain my bruises by saying that I had been swinging on the vines and one of them broke.

I began having trouble getting on and off the school bus. This was a problem at first, since the bus driver advised me to get more exercise when he saw me getting extremely tired just trying to get up the few steps on the bus. Of course, exercise was not the solution at this point. Fortunately, this was solved shortly when they equipped the bus with a lift for wheelchairs. My old friend Pam, who I had known since the third grade, was wheelchair bound, so we both had to use the lift. I did not mind using the lift at all even though I was not yet confined to the wheelchair. Like most young boys, I was fascinated by the mechanism, and I enjoyed the ride. But it also enabled me to help Pam and the bus driver at the same time, which made me feel quite useful. Since we both used the lift, the bus driver would allow both of us to ride on it together. The bus driver would first unhook her chair from the locks and I would push her over to the lift and then on into the classroom. In the afternoon we would reverse the process. This was handy for the bus driver who could concentrate on working the lift and not having to hold the passenger

from rolling off. Even though my condition was deteriorating, I was not yet wheelchair bound, and I could help in this way.

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While the physical problems were hedging me in, my fifth grade year was not a complete downer. There were a number of friendships that were nurtured at this time that I fondly recall, especially with my classmates who were in wheelchairs. In particular, Pam and I became particularly close in that she rode the bus with me. There was also Sherri and Doug. Friendships that had begun in third grade became closer and closer now, and these would last the rest of my life. Doug and I became such great friends that we began taking turns spending the afternoons at each other's houses (as I had done with Bart and Thomas in third and fourth grades). Of course, there were other students in the classroom at this time, some old and some new; and while I was friendly with all of them, these were the three that I spent most of my time with.

It was during this time that the TV program MASH was popular, and the four of us would sit in front of the tube every afternoon and watch it. We got so familiar with it that when we were at school we would take any spare time that we had and act out a scene from the show, or make up our own episodes. It was a cross between remembering the characters and making it up as we went along. Either way it was great fun and a stretch for our imaginations. Fortunately, our instructor had the patience to put up with such childhood foolishness.

It was also during my fifth grade year that I can began to get uncomfortable about being a child growing up in an adult world. For one thing, if you got accused of doing something that you did not do, there was very little that you could do about it. The teacher from the next classroom came in once and announced that they were showing a movie next door and wondered if any of us would want to join them. Our teacher said that this was OK; however, since we were starting our math course we would have to make this up later. Also, those that stayed would get some other special treatment later. Well, math not being my favorite subject, this was not a difficult choice: I jumped at the chance whether I would have to make it up later or not. So a couple of friends joined me and we went over to see the original version of Born Free, which, I recall, was quite full of excitement and adventure.

I enjoyed the movie so much that when I got back into our classroom I began telling my friend Doug all about it – how great that movie was that he really needed to see it. Well, right away the teacher's aid picked up on this and thought that I was trying to tease him. She jumped all over me, indicating that he would get his own special privilege later. I really felt hurt and offended because she had completely misunderstood my intentions. I was not trying to tease him – just trying to share a fun experience with him. But at that point there was nothing that I could do except go to my desk and get on with my work. There are times when there is no way to explain your way out of things, and it is better just to get on with it.

One of my favorite classes that I took during the fifth grade was geography of the United States. The way that our teacher handled this class made it very interesting. Instead of studying all of the states one at a time, she had us study them region by region. We started with the New England states and proceeded on around the US in a counterclockwise fashion. As we studied these regions, we would learn such things as the state capitals, what products the state was known for, and the major cities, rivers and other features. I enjoyed this class so much that often

during my free time I would draw the states according to the map that the teacher had placed up on the wall, memorizing the shape of each state. Also, when the library had a reduced-price book sale, the first thing I purchased was a puzzle of the United States.

I also learned in my geography class about my teacher's sense of fair play. After studying each region of the country we would have a test on all of the geographic features that we had gone over. When we got to the southern states, she asked us the capital of Louisiana. I know that it was Baton Rouge. This was easy for me to remember, since it was where my grandparents and cousins lived. My problem was that I was unable to spell it. So I skipped it and went on and finished the rest of the test. When I got through I told the teacher that I had trouble spelling Baton Rouge. She was busy at that time and told me that she would help me in a few minutes. After a few minutes I got tired of waiting and decided that it would be much simpler if I just got out the book and looked up the way to spell it for myself.

When I handed in the paper, it was spelled properly. She said: "I thought that you said that you did not know how to spell it." In my naiveté I just told her that I had just gone ahead and looked it up in the book. She indicated that this was not permissible during the test and that she would have to mark off points for it on the test. Obviously, I was quite dumbfounded and downcast, since it never occurred to me that what I did could be construed as cheating. She had to leave the room for something, and one of the teacher's aids noticed that I was upset and asked me what was wrong. I told her what had happened, not realizing that the teacher had already graded the tests. The aid went and checked my test and told me that I had gotten an A so I need not worry about it. Clearly, she had given me the benefit of the doubt – perhaps because she knew that I knew the answers, and perhaps she had been there herself at one time or another. Actually, she was also doing me a favor by placing a little fear in me, since that was the last time that I would crack a book during a class, even if it was just to get the spelling right.

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Usually when people look back to their memories early in grade school, one thing that stands out is the first teacher that they fell in love with. But for me it was not a teacher, it was a student teacher. Of course, looking back on it, I recognize it as a normal young person's crush. However, in this case it also turned into a great and warm friendship. She was young, pretty and was easy to talk to. I recall one day I tripped and slammed my knee into the wall. This was not nearly the injury as I had sustained in the grocery store; however, she took great concern in my problem and was the first to come to my aid. We had many great conversations. However, my puppy love did not become any kind of embarrassment for either of us, since our age differences were obvious to both of us. So we just remained as a close mutual friendship. There were times when she had to discipline me, but this never got in the way of our relationship – she always did it in a very positive way.

Being a student teacher is one of the last requirements in getting a teaching certificate. The many times when we had student teachers in our classroom, there would always be a supervisor from the university to assure that they were getting the right experience with their internship. Most of the disabled students who I grew up with in our special ed class learned to cope with their disabilities with a sense of humor. We would poke fun at each other, and often at ourselves, and it was quite healthy to be able to laugh at yourself and one another without causing any pain. The student teacher began to pick up on this as well. One day when the student

teacher's supervisor was there, she was trying to teach me a particular math problem. Math was not my favorite subject, and I was having a difficult time getting the method for this particular type of problem (probably because I was not paying attention). So, in the spirit of good, clean fun, I looked up at her supervisor and said: "Give her a bad grade." He responded with a formidable, deep voice: "I am afraid I will have to."

As far as my math problem was concerned, I soon got that resolved. However, to my shock I discovered that the supervisor was not teasing. He gave her a bad grade despite the fact that she was doing an admirable job. The problem had been my disrespect, although I am convinced that maintaining a sense of humor is essential. The problem was in my assuming that the supervisor would take it in the spirit that it was given. The appearance conveyed was that the student teacher did not have the situation under control. This was quite upsetting and embarrassing to me, since I did not want to get anyone into trouble, especially someone who I had developed an innocent crush on. I was quite concerned that she would have nothing else to do with me after this. I knew that I would have to apologize, but ...

The scene seems as one out of an old black and white movie. Our teacher every Friday would allow us to bring records from home, and the situation fell on one of those days. Each time that I would approach her to apologize someone would put on a record. I recall *How Deep is Your Love*, by the BeeGees ... it seems as if it went on endlessly. I finally got it out, and to my surprise, she accepted with little evidence of any harm. Clearly she did not hold a grudge, our friendship continued, and she never brought the incident up again. The lesson was quite clear: there is a time to joke around and a time to hold your peace.

There was one more thing that was of significance as fifth grade came to a close. A couple of weeks after school let out for the summer, I went into my first bad spell of depression. It only lasted about a week but its misery was significant. Though I am not a psychiatrist, looking back I often wonder if, in the back of my mind, I knew that my condition was soon to worsen.