

1

Keeping Up

My name is Don Fulk. I was born on February 17, 1942. When I was three years old, I contracted spinal meningitis, which left me profoundly deaf. When I was eighteen, I had a swimming accident and became a quadriplegic. This is my story.

Canals run like rivers in my small hometown of Colton, California. When I was eight years old, I often went with my brother, Paul Howard, and two neighbor boys to the canals, where we waded in the water and caught crawdads. We filled our buckets with the crawly little things and took them home. The neighbor boys' father cleaned them, keeping the tails, and throwing out the rest. I knew that the family cooked and ate them. I decided I would never go to their house for supper.

Wherever the other boys went, I followed—always behind. They discussed their various plans for adventure, but because I couldn't hear and talk, I was never really included in their decision making. I only followed, curious about where they were going and where they might lead me.

I remember once they came upon a canal in the midst of tall weeds. I was not far behind. The only means of crossing the canal was a wooden pole stretched between the banks, on which the boys lightly skipped across. I happily ran to catch up, but when I came upon the pole, I hesitated. The other boys waited on the far bank, gesturing to me to hurry up. They grew impatient and began disappearing into the weeds and bushes.

The only way I could cross was to get down on my hands and knees, grasp the pole with both hands, and slowly crawl across. My heart beat like the wings of a hummingbird, but I slowly and painstakingly inched my way along, reached the other side, and ran to catch up with the other boys. I didn't know then but later came to understand that my deafness affected my sense of balance.



Don on bicycle with brother.

We journeyed on and eventually came upon a bridge with a train track. We looked over the sides and saw some men on the ground. Some were asleep, and others were cooking over a small campfire. They spied us and suddenly began picking up rocks and hurling them at us. I guessed they didn't want us to bother them or the boys had said something to them that they didn't like.

In those days, I had lots of fun making and playing with homemade toys, such as slingshots, wooden guns with rubber bands cut from old inner tubes, and makeshift boxcars. I used to play outside a lot, without shoes or shirt, with an old discarded tire. I remember rolling the tire beside me as I walked through my neighborhood, past the old wood-frame houses lining the dirt road that stretched away before me.

Sometimes I helped the landlord fill bottles with homemade beer from a large wooden barrel in his secret cellar. I thought it tasted awful and added it to the list with the crawdads. We boys also spent many hours playing "war," taking sides and throwing stones at each other.

In these ways, I filled my silent days before we had television. But after the television came, for me it, too, was silent.

Sometimes my brother and I would walk together to a small town nearby to swim in the neighborhood pool, but most of the time I went alone. I loved to dive and search the bottom of the pool for stray bobby pins or lost pennies. Often I would bring a dime with me to the pool, flip it into the air, watch it sink through the water, and dive in after it. I did this over and over. But one time, I flipped the dime high into the air and watched in dismay as it disappeared into the top of a fat woman's bathing suit. As she dug it out from between her huge breasts, I quickly dived under the water in order to avoid embarrassment. I decided to let her have that dime, no questions asked.

One day later that spring, my parents began packing suitcases and food baskets and putting them into the car. What's going on here, I wondered. Where were we going?

I tried to ask, but no one understood my sounds or seemed to want to bother with me. Of course, I probably would not have understood if they tried to explain.

We all got into the car and drove. And drove . . . and drove some more. It seemed an awfully long way, and I became quite bored. There was nothing for me to do except sit in silence and watch out the windows as the scenery grew increasingly monotonous. After two whole days, we arrived at somebody's house somewhere. We entered and I stared as my family hugged some people, and everybody started moving their mouths, seemingly all at the same time. I knew they must be nice people because they all smiled a lot, and they even hugged and kissed me, but I had no idea who they were. I found out years later that we were in Terre Haute, Indiana, and these people were my grandparents and aunts and uncles.

Back in California, we lived in a small house we rented from the family who lived behind us. We shared a backyard full of chickens, with a vegetable garden, and cornstalks. The landlord's sons used to play with Paul Howard. They built a secret clubhouse, using a hole in the ground about four feet deep and ten feet square. They made a roof with cardboard boxes and covered it with tree branches. They would go inside and conduct their secret business.

I longed to go in with them, but they never let me. One day I got so frustrated and angry with them that I picked up a heavy log, lifted it high over my head, and heaved it at the roof of the clubhouse. The entire roof collapsed with a poof of dust, and before I could plan my next move, the boys began chasing me.

My mother was in the backyard hanging clothes on the line, and I ran for the protection of her skirt. The other boys' mother saw what happened and came out to speak to my mother. From behind her skirt, I could see their mouths moving at each other. Their mother soon left, and a few weeks later we moved to San Bernardino. I think their mother was angry that day, and I have often wondered if the move might have had something to do with me.

We moved to San Bernardino in 1952. I was ten years old and had never attended school. I think my parents didn't really know what to do with me. I didn't know how to relate to them, and I did not feel particularly close to them.

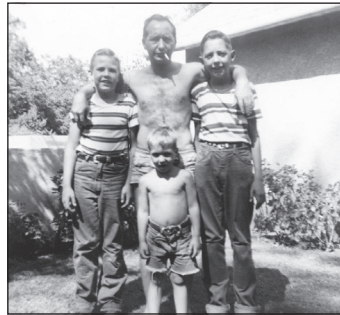
2

Communication

That year, 1952, I had my first encounter with school. On the first day, before I left for school, I learned my first word. My father took me aside and wrote something on a piece of paper. It read D-O-N. He pointed to the paper and then to me. I could hardly hold back my excitement. I had an identity. I was Don.

My father took me outside to wait for the school bus, and he rode with me to school. I don't remember the name of the school, but it had one classroom, seven students, and one teacher. The other kids in the class stared at me because I was new. But I realized they were like me when I saw them talk to each other with their hands instead of with their mouths. They used simple home-made signs that I picked up quickly.

My first day was a busy one. Right away, the teacher worked with me on making sounds and words with my voice and saying the other students' names. After pointing at pictures or various objects, the teacher showed me how to place my tongue, teeth, and lips while pushing my breath through my vocal cords in an effort to produce the proper sounds for each word. The teacher and I also placed our hands on each other's throats, feeling for vibrations. She tried to teach me the song "Happy Birthday to You."



Don's father with his three sons.

However, even as I started school and began learning language, communication was an increasingly frustrating and embarrassing problem. Once, I was playing outside with two boys who lived a few houses down the street. I noticed that it was getting dark, and I wanted so much to tell them that I wanted to play with them again the next day, but I couldn't. For a few moments, I struggled with the problem of how to communicate. My eyes came to rest on a long stick lying nearby on the ground. I picked it up and drew a picture of the sun in the dirt. I motioned to the picture in the dirt, then toward the sun setting in the sky. I moved my hand slowly down, down, down, to indicate the sun setting, then I pantomimed going to sleep, then waking up, and running out to play. The other kids stared at me in wonder. They thought I was crazy or, perhaps, pretending to be some kind of goofy Indian guide. They left me standing there. I walked home and went to bed, frustrated again.

On another occasion, my brother motioned for me to follow. I followed him all the way through shortcuts, past trees, over a river bridge, until we arrived in town. I followed as he crossed streets, though sometimes I feared for our safety. At one point I screamed when it looked like a truck would hit me at a traffic light. I didn't understand the meaning of traffic lights and only learned about them later from my lip-reading teacher. When we appeared to have reached our destination, I realized that my brother wanted something because he gave me a dollar and tried to tell me something, but I didn't understand what he wanted. Finally he gave up, took the bill back, and ran off to catch the bus. I was left standing there. I never did find out what he wanted of me.



I have always hated Thanksgiving because I felt more alone then than at any other time. It was a day when many people came to our house and talked and laughed, and we all sat at a big table to eat lots of food. Thanksgiving scared me. I couldn't communicate with

anyone, and they didn't try to communicate with me. I would sit patiently at the table eating my food, every now and then glancing around at the happy faces, and feeling terribly alone. Mouths constantly moved—if they were not eating, they were talking.

I suddenly realized that I needed to go to the bathroom. I wanted to leave the table, but I was afraid. I wanted to ask my mother to be excused, but I had no words. I shifted in my chair, uncomfortable and frightened, until the inevitable happened. I waited patiently for the meal to end. When it did and I stood up from the table, the awful evidence was there on my pants and on the floor. I ran to the bathroom, hating Thanksgiving all the more.

Occasionally, communication was a simple thing. Some of us kids used to make parachutes out of a piece of cloth with strings attached to each corner and the other end of the strings attached to a heavy nut from some old bolt. We would fling the small things into the air and watch them float gracefully to the ground.

I watched them, wondering if I could fly like that. Suddenly I had an idea. What about using a big sheet? I figured that if a small cloth could carry a nut, why couldn't a much larger sheet carry another kind of nut—me. I ran home and got a sheet. My aim was to jump off the roof of the garage and float gracefully, like the smaller parachute, to the ground. I thought it would be great fun. Halfway to the door, though, my mom caught me. She grabbed the sheet and looked at me sternly, her mouth moving, and her finger pointing. She had read my mind, and she foiled my plan.

Ever since I was very young, I have had vivid dreams and nightmares that I remembered as though they actually happened. One in particular that I still remember had to do with a butterfly. I wanted it so very much because it was the most beautiful butterfly I'd ever seen. I chased it everywhere until it landed on top of a huge flower. I snuck up on it, and when I tried to grab it, the flower's petals closed up with the butterfly still inside. I began peeling back the petals one by one, seemingly for hours and hours. With still more petals to go, thousands of bees suddenly came out of

the flower and attacked me. I fought them off with my pillow. My mother quickly appeared at my bedside, helping me to calm down and go back to sleep.

Dreams such as these continued until I was in my thirties. Looking back, I wonder if my dreams had to do with the terrible frustration I felt and the loneliness and isolation of deafness. I think they might have had to do with my sitting at the dinner table night after night, head bowed, feigning an intense concentration on my food, eating quickly and silently while those around me engaged in happy conversation. I also think the dreams might have had something to do with my painful awareness of the impatience on the faces of my brothers and sisters and friends when I struggled to tell them, with guttural sounds and gesture, about things I saw or did. And I think, most of all, the dreams might have had to do with my longing to share deep personal feelings with my mother and father, only to have my efforts to do so stifled by fist-clenching frustration.

I could see that the sounds I made caused heads to turn and eyes to stare. I could see the concern on my mother's face when she heard my initial sounds. But after getting someone's attention, what could follow? I knew that I could think and feel and dream like anyone else. Thoughts, ideas, and feelings were there inside my head and my heart but the others didn't seem to know or understand this. In those early years, I didn't know how to tell them. I was so often filled with a sense of separation and bewilderment. Who was I, who are these people? Why am I different? How old am I? Where do I live? I had all these questions, but I didn't know the answers and had no way of getting them.

3

The School for the Deaf

In 1954, when I was twelve, my parents sent me to the California School for the Deaf at Riverside, which was not very far from San Bernardino. I lived in a dormitory with other students my age. I began to learn things, in and out of the classroom. I began to learn that I would have to watch out for myself.

One of the first things I had to learn was how to get to school. My mother made the first trip with me by bus from San Bernardino to Riverside, but the next time I went home on a visit, she let me make the return trip alone. I arrived in Riverside, but I didn't know the name of the bus to take from the station to the school, ten miles away. I still could not write, so I couldn't ask anyone. I started walking. I didn't know the name of the street, but I knew the general direction, and I knew the school was on a hill. I walked and walked, even climbing trees to scan the horizon. Finally I spotted the hill and became so excited that I ran the rest of the way. Before I entered the campus, however, I sat down on a rock and rested for a long time. Then I noticed the sun was beginning to set, and I thought, I better hurry or I will be late for supper. I was relieved that I had made it.

I also learned that there would be boys like King. While outside playing with the other deaf boys, I noticed one boy with bronze skin and a duck-tail hairdo who seemed to be the leader of all things. He strutted around like he owned everything and everyone. His real name was Victor, but I decided to call him King.

One time our housemother, who was sixty years old and also deaf, appeared at the doorway with a huge bowl of popcorn.

Almost before I could blink my eyes, the boys charged her, with King in the lead. Popcorn flew in the air, as she took off, leaving it all behind. I believe she was genuinely frightened. The boys continued to push, shove, and fight to get that popcorn. All I could do was stare in shock. They looked like a bunch of animals. I stood and watched until there was nothing left outside the door but a shattered bowl.

Some mornings at five o'clock, King, who slept in another room, would saunter into the room where several boys and I slept and start turning beds upside down to jolt us out of our sleep, and he would persuade us to help with one of his schemes. Everyone was afraid of him, and although we wanted desperately to go back to sleep, most of us would readily agree to get up and help him with his little game. He didn't worry about anyone hearing the ruckus because the house parents were just as deaf as the boys. Since I didn't have sign language skills on par with the other boys, I was able to stay out of King's circle, so I usually ignored him and went back to sleep.

I was not afraid of King, and I let everyone know this. Word got around to him, which made him angry and he began continually challenging me. Once, he took half an orange, rubbed it in my face, and sprayed it on the walls of my room so I would be responsible for cleaning it up. He tried my patience one too many times, and I pushed him. Surprise spread across his face, and he came back at me. The other boys gathered round, curious to see who would win. Before we could determine a winner, though, one boy waved frantically at us to warn us that the housefather was coming, sure that he would punish us. When the housefather arrived, he asked what was happening.

King and I both replied, "Nothing," and the incident passed. But after that, King left me alone. I think he simply faced facts: I was bigger than he was, I was strong, and I was not afraid of him.

One day I saw an awful scene. One student was mentally challenged, and a bunch of the other boys made fun of him. About eight o'clock one night, four of the boys walked into my room, this

boy following, on their orders. They formed a circle around him, laughing and signing fast. I didn't get all that was said. Then they opened their pajamas and urinated on him until his pajamas were soaked. The confused boy stood there, flinching, and I stood there, watching. I couldn't believe what I was seeing.

When the boys had their fill of "fun and games," they forced the poor boy to clean the floor. Then he slowly stood up, his face contorted, and left the room. The other boys laughed and talked about the fun they had. I turned away to go back to my bed and do my homework, but it bothered me. I felt upset and outraged because I had felt helpless to do anything about it. Those boys were at a higher level than I, and they could communicate more quickly and easily with each other. I knew that I should stay out of it, and I felt that it was not my place to say or do anything.

I thought, "When will it be my place?"

I was also learning things in the classroom. I started learning sign language every day from the other kids. My roommate, especially, was a huge help. Now that I was around sign language all the time now, I was picking it up fast. About the time I turned thirteen, I learned the days, weeks, and years, and how to tell time. I learned numbers and how to add and subtract. But I still didn't know how to write, so the teacher would sometimes write letters on the blackboard for me to copy and mail to my parents. I was fascinated to discover the names and amounts of coins. Here was the penny, the nickel, the dime, and so on. How wonderful to be able to recognize them and to know their value! Before, I could only lay down a bunch of coins on the counter and let the salesperson take his pick, and trustingly accept whatever change he offered. Now, I hoped I would be able to sell newspapers on the street.

Paul Howard soon began to learn to fingerspell, forming the letters of the alphabet on his hands in order to spell words. But it was several years before my parents learned any sign language. My father eventually learned to fingerspell. So did my mother, and she learned a few signs.

The autumn before I turned thirteen, I moved into the “Upper 111” dormitory. Dorms were assigned according to age groups. I was at the age where I started copying other boys’ style of dress and their duck-tail hairdos. My hair looked like wax. I wore my collar upturned and my trousers low around my hips. With my penny loafers (with fringe), I thought I was cool and was sure that my new image would help me become more accepted by the others.

One night, something rather interesting happened. Around midnight, one of the boys tapped on my shoulder to wake me up.

I looked up and moved my hand in the sign for “what?”

He put his finger across his lips and gestured for me to follow him. We crept down the hallway in the dark and sat down on the floor with some other boys. I asked again and again, but they cautioned me to be quiet. Then one of the other boys opened a magazine and turned on a flashlight. The boys anxiously gathered round to look closer. In the glow of the flashlight, I saw that the title of the magazine was “Playboy.” When I saw what was inside, I felt strange. I was shocked to see a woman’s large breasts confronting me from the pages. I was confused and unsure—things were not as I thought.

“Where is her penis,” I asked.

The boys looked at me and grinned.

“They don’t have a penis, silly,” one of them said.

This was a surprise to me. I just stared at the pictures and wondered, while I gawked. Suddenly a beam from another flashlight appeared down the hall. We all jumped up and ran to our beds, one boy taking the magazine with him, while a man with a big ring of keys on his belt passed by without noticing anything.

Back in my bed, panting from my run and staring into the darkness, I began thinking about the pictures, about the differences between men and women, and about where I had come from. I had always thought that I came from a basket. I had seen the cartoons. The baby kittens were always in baskets; the stork always brought the baby in a basket. Now, from what I understood of the boys’ fast signing in the dark hallway, they were telling me that the

basket story was not true. I was totally confused. I felt pressure in my mind to solve this problem. But sleep overcame me, and I did not solve it that night.

One day in school, they showed a picture of a family tree. I looked and studied all the branches coming out, going this way and that. There were the words “aunt” and “uncle,” foreign and without meaning. And I became even more confused.

I played a lot of football in the years I was at the school. One day, our football coach told us we would get uniforms. I was very excited because we had not had any uniforms before. That night I had another dream. I vividly remember playing a thrilling game of football. Somehow, during that dream, I got up out of bed and hit my head against the wall. I blacked out and fell back on the bed. When the housemother arrived to wake us up for breakfast, she had to help me up. I had a very large bump on my head. Too bad I didn't have my helmet in time for the dream. I never did get to wear my football uniform. My family and I moved away before the team played its first game with uniforms.