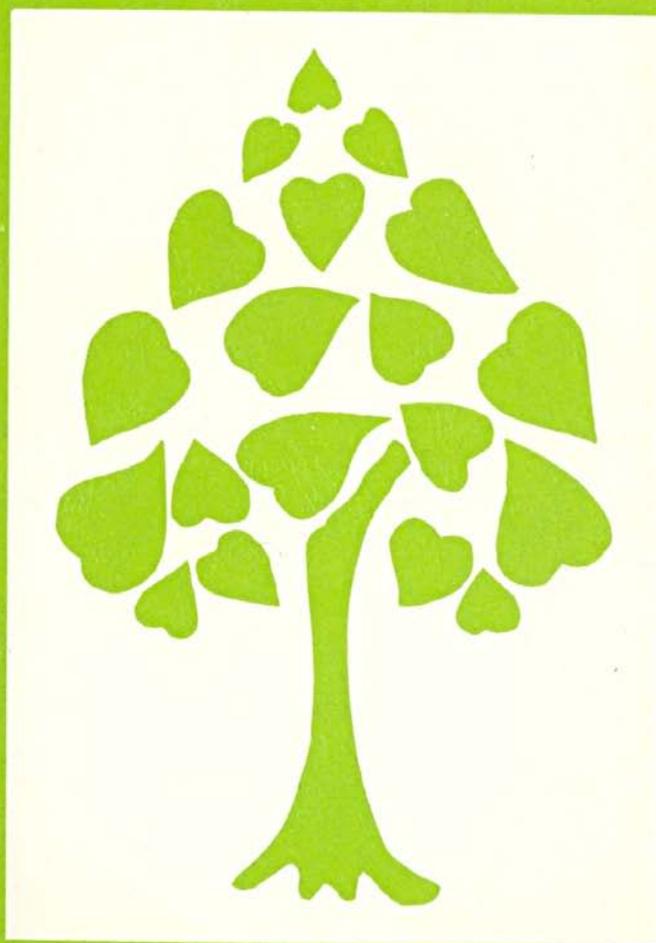


**MY
NEW**

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**JUNE
van LINT**

MY NEW LIFE

June van Lint

First Printing
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June van Lint at her typewriter

Photo by DeWayne Tappe

I dedicate this book to my children—Larry, Kenny, Linda and Karen—who had to grow up fast with much less help than I wished to give.

ACKNOWLEDGMENT

With loving thanks to my husband Vic for his patience and care in helping me organize the material for this book. I will always cherish his sense of humor which came to the rescue in moments of frustration.

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THE ACCIDENT

I did not expect to write a book. I pictured myself as a normal housewife, well occupied with home, husband, four adopted children (ages 2 to 9), PTA, choir, and the church couples' group. Then in August 1966, my life changed drastically.

I never dreamed when we left on our vacation that it would be more than ten months before I came home again. Nor that I would be almost totally paralyzed.

I was driving our station wagon and trailer while Vic, my husband, and two of our four children were trying to sleep. The other two were chattering. On a downhill stretch a combination of circumstances caused the trailer to fishtail. The car and trailer swerved again and again, each time more violently, until finally the trailer left the road and the wagon rolled over, once completely, in the middle of the road right down the center stripe.

I injured my neck and was taken to St. Charles Hospital in Bend, Oregon, on the day of the accident, where X-rays were made. I had "a fracture dislocation of C5-6," and "apparently slight weakness of the forearms but otherwise no neurological abnormalities." (Patient History, Scripps Memorial Hospital, 9-1-66.)

OREGON HOSPITAL

I spent time in three hospitals before coming home.

The hospital in Oregon had a very generous visiting policy. As long as there were not too many at a time, Vic arranged with the authorities to allow the children to see me during visiting hours.

My husband, Vic, is a physicist. At the time of the accident our oldest boy, Larry, was nine years old, strawberry blond, very talented and all boy. Kenny was seven, platinum blond, equally talented, inquisitive, quick-witted, and the family comedian. Linda, our five-year-old girl, had beautiful red hair, and also appeared to be very bright as far as we could tell from kindergarten. Karen, a petite sweet-faced, dark haired, blue-eyed girl of almost three, expertly played the part of the family baby.

'Crutchfield tongs were inserted and traction up to 40 pounds was instituted and the fracture dislocation was reduced. The weakness and paresthesias improved and the patient was taken to surgery approximately ten days later for fusion of the cervical vertebra. This was accomplished uneventfully under general anesthesia. However, the patient never regained consciousness from the surgery, although at times it appeared as if she would do so.' (Patient History, Scripps Memorial Hospital, 9-1-66.)

During the surgical operation a blood clot moved up into my brain stem and left me totally paralyzed. At first I was in a coma, showing no signs of memory, perception or understanding.

I am told that during the first six weeks after the operation I appeared to be asleep with my eyes open. I lived in a world of constant nightmares. So vivid were they that more than a year later I would remember them in stark detail.

During our stay in Oregon, Vic stayed with me during the day; he served as my private duty nurse except for the night shift. Of course, after my operation Vic didn't want the children to see me, so he arranged for them to be taken to my sister.

Being moved regularly is particularly important to a totally paralyzed person. Lying immobile in one position, even for a few hours, can produce very painful body sores at pressure points. A neck injury adds extra complications. In the Oregon hospital my head was in traction, so I could only be moved by turning from my back to one side and to the other side. This process usually required three people to turn my 5 foot 11 inch, 155-pound frame and keep my neck straight throughout the process. In spite of the care, I developed three sores within the first day, on the back of my head and on the point of each shoulder. Months went by before they healed fully. When my neck was later held in place by a brace, the turning became simpler. Meanwhile, the need to be moved and the turning process preoccupied much of my dreams and my waking thoughts.

From the beginning of my brain injury, communication was my most serious problem. Vic immediately tried to see if I could use what appeared to be a little control of my eyelids to answer his questions. It was difficult: my eyelids would also move involuntarily. At first my answers made no sense. I couldn't even pick out how many children we had or their ages, or how long we'd been married. Toward the end of my stay in Oregon things improved. I picked out the right name of a friend who came by to visit. Finally, when my mind cleared up, I used my eyelids to pick letters out as Vic or a nurse recited through the alphabet. In this way I could spell out words and phrases. At last I could tell them what was bothering me and also ask questions.

When they heard about the problem, my mother and stepfather drove up to see us in Oregon. I didn't show any signs of recognizing them, so there wasn't much for them to do. Later my sister's mother-in-law came by for a brief visit. Again, I didn't respond, but Vic was really encouraged when I showed with my eyelids that I could pick out her name. At least I seemed to begin to understand who was there.

I'M CONFUSED

Toward the end of our stay in Oregon, Vic started talking about going for an airplane ride home. I thought I was going to sit up front with Vic and the pilot. Boy, was I angry when I found out different. I was squeezed through the door lying down on a stretcher, put on a very uncomfortable, sagging-in-the-middle seat, tied down and kept attached to some surgical tubing. I felt as though I was sinking lower and lower into the middle of the seat that I was lying on. I was irritated because whenever I tried to climb out of the low part of the seat, I seemed to dig a bigger hole in it. It was like a bed that sags in the middle and you keep rolling toward the low point. Only I was not rolling, just sinking and I couldn't seem to climb out. I thought there

were three men on the plane with me: Dr. Bethard,¹ the doctor from Oregon, and Vic. I remember being very angry because Vic kept popping up to take pictures out of the windows of the plane and I couldn't even see out the window. We seemed to be flying attached to a cord, because the doctors decided we should fly at a certain altitude. We landed at the airport in San Diego and they started to unload me. I looked up and thought I recognized a friend, but he looked down at me to show his white teeth and a knife², so I quickly lay back down.

I was put into a panel truck with little holes in the ceiling. After everyone with me was settled we started to go and I realized we were not going home at all. I started yelling, "I want to go home," and all the others said was, "It is midbrain damage all right." I was taken to what I thought was a mental hospital. A man put me in a room which he said was his old room and said that I would be fine. On the way in, I saw a lady with her arms up looking in a mirror while combing her hair in bed and I thought "before long I'll be doing that." Meanwhile, other people were showing Vic what a modern hospital this was, how you could just press a button and change the color of the room, or the tilt of the bed. This was the beginning of my five-month stay at Scripps Hospital in La Jolla.

When I first went to Scripps, I wasn't conscious, but I thought I was and couldn't understand all the strange things that were happening to me. For one thing, there was that painful jab with regularity. They couldn't be shots: why would they want to give me injections? So why were they sneaking up and jabbing me? Didn't they have anything better to do? And why was someone always with me, as if I were a prisoner? I heard people say that this was a hospital. It seemed more like a jail. But even in jail they didn't constrain you this much. I could feel the big thing around my neck to keep my head still, but what did they have on my arms and legs? And why that tight feeling on my arm followed by the whiff, whiff, whiff? What was a dog doing in a hospital? And why this voice urging me to fight to open my eyes, especially when it was very painful to do so. Why this peculiar feeling of long hair on my face? I had short hair.

When I finally managed to get my eyes open a little, I found that everything was out of focus. There was a shock of long, red hair hanging over me. This couldn't be a nurse, could it? They all had their hair pinned up. And when I did get my eyes open, what was the reward? A series of electrical shocks that closed my eyes and sent me spinning. Where was I? I heard the sound of trays rattling, but no one came in and offered food to me. And yet I felt my stomach filling up even before it became hungry. I tried to ask about all these strange events, but found my jaw to be closed tightly. I tried to make a sound with my mouth closed. No sound came. I could do nothing but listen and wait.

Among the strange noises there were sounds of gaiety. What did it all add up to? Nothing made any sense. Every hour my stomach magically filled up very quickly; a most

¹ Dr. Bethard, the medical director at General Atomic where Vic worked, had visited Oregon a week earlier to make the arrangements for the trip, but was not on the airplane. The airplane steward was the only extra person in the cabin, other than the doctor from Oregon, Vic and me.

² John Chiment, a friend who worked with Vic, met the plane together with Dr. Bethard. He certainly isn't known for carrying a knife.

peculiar sensation, even among all the other strange happenings. I couldn't turn my head, but I soon discovered that every hour a person dressed like a nurse came into view, moved the sheet aside, and put a funnel into a tube and poured a strange concoction. Then I had the comforting sensation. Somehow it seemed to be familiar!

When I first came to Scripps Hospital I had a dream about moving into the hospital. It went something like this. I was moved from the plane to the hall of an old theater building, which was supposed to be the hospital. A nurse with red hair wouldn't let me go to my room until I was turned in with a bunch of other people. After I was turned, I was at the bottom of all the people and it hurt very much. The redheaded nurse brought her flashlight over to try to find out why I was yelling. But she never found the person who was hurting me. To be turned was like having all the parts of my body thrown up in the air and you wondered whether they would all come down and land in the correct place.

Mother and Dot, my younger sister, were always in the bathroom trying to scare me. This time we stopped right next to the bathroom. Mother and Dot were rolling empty coal cars up and down the aisle to the bathroom. Finally, my Father decided to stop them. Then they whisked me past the bathrooms and past the place that had formerly been the snack bar and on to my room.

I was taken at one point to the psychiatric department of the hospital, where I listened to hours and hours of music and then was told that I was fine. All I had to do was get up and walk out, but for some reason I was frozen to the spot. Because I couldn't move, Arlene Ragan, a good friend, came up and did physical therapy exercises to my legs. She made them bend up so far that I thought they were going to fall off. Then the audience, who seemed to all be people from Northminster³, presented me with a crib and some beautiful baby blankets and in the crib was big Larry.

At Scripps I thought I was brought into the room by helicopter. There were two helicopter passageways into my room. These passages were behind me in the two back corners of the room. Vic also used these passages to come and go from General Atomic by helicopter when he came to see me⁴. This was to save time. I could hear him coming up the passage and then he would stop for a while and then start again. Why, I never figured out.

The kitchen, I found out later, was across the hall from my room. There was a jog in my room of which the other side turned out to be the bathroom in the next room. But I was convinced that it was the floor kitchen and that installed in that wall was a spy hole where people could look into my room. It was this room Mother and Dot managed to get into and operate a mind-reading machine and spy on me and laugh at my thoughts as they were printed on the machine. Vic didn't seem to know the machine existed and I kept trying to tell him to get it away from Mother and Dot.

I was convinced that next to this kitchen was a waiting room filled with all my family,

³ Northminster Presbyterian Church, of which we were formerly members, and among whose members are many of our friends.

⁴ General Atomic. where he worked, is only about two miles from Scripps Hospital.

laughing and talking and eating and drinking. I couldn't understand why they wouldn't let them come into my room, as long as they had come so far to see me. I later discovered that there was a waiting room on the floor, but it wasn't next to my room. The laughing was coming from hospital personnel, but to me their laughter was identifiable with each member of my family, especially the high-pitched laugh characteristic of my mother. The dishes I heard rattling came from a floor kitchen across the hall. I thought I could hear everyone, including Muriel Joyce and Beverly, my stepsisters. I wondered how they all got time off and why they were always laughing when they had come so far and couldn't even get in my room.

One of the dreams I had when I went to Scripps Hospital was that I could see this flaming red hair. I was telling everyone how mean Vic was to experiment with tying up my muscles. This redheaded creature told me she was my friend and that if I would go through the research lab with the bugs and animals I would come out all right. Then she lowered me into a swirling pond with many, many animals and I came out of the water on a conveyor belt and into the lab. I decided this was no friend of mine. I also dreamed that I was sinking lower and lower into a pile of people and being crushed, and the redheaded nurse was deliberately ignoring what was going on. I thought Vic would be here soon to help me. But when he came he only talked to the nurse while I drowned in people.

I had dreams for about a week after I went to Scripps, one of which was about me going through a big sewing machine. The red haired nurse was there standing right next to Vic and they were guiding me through this human-sized sewing machine, sewing all the wrong parts of my body together and sewing down folded-up places that had been previously sewed incorrectly, or sewing within one stitch of a big mistake and then quickly turning away from the mistake just as it looked too late and saying, "Well, we made it that time, let's try it again." "She will be all right after much very painful exercise; our mistakes won't even be noticed after she corrects them through exercise." "Aren't we good to have done such a good job?" "We are very proud of ourselves."

During my first few spelling sessions with Vic I spelled out phrases inspired by my dreams. Of course, I didn't realize they were only dreams. Vic didn't understand where they came from, either, so he was a bit shocked. A few examples are:

*Get mind read machine---You go kitchen---Mind read machine---Mother in kitchen---
Operate mind read machine---Hear it
You tell doctor tie chords---I am experiment
Pins sticking into head---You put them in---Chord in head
Body cut up*

NURSES and NURSING CARE

Before I realized I was paralyzed, I used to wonder what made the sheet so heavy that I couldn't even budge it. It took many months of inching my left hand along before I could move the lower part of my arm to touch my breast and a lot more practice to raise my arm enough to get over this mountainous object. I'm really quite flat, but any curve was a large lump to me.

Before my accident, I had fooled around a little wondering what it would be like for a limb not to move when you told it to. But I had never thought anything about the way I talked. Talking was simply taken for granted as part of being a human being. I had heard of children having problems with speech or being born mute, but I don't recall ever hearing of an adult losing his or her voice, although I am sure it's not unique. So the fact that I couldn't communicate was a real shock to me. It took quite a time for me to realize that people couldn't understand what I was saying or why they didn't respond. I had to learn to understand and accommodate to my incapacity, and I had to learn to live in a world controlled by nurses.

I first discovered Nurse Rhea Clark (this is a fictitious name) in some of the dreams I had at Scripps Hospital while still in a coma. When I first came to the land of the living, she appeared again as a shock of flaming red hair telling me I must fight to keep my eyes open. In the days that followed, I soon discovered that she was young and scatterbrained, but saw herself as grown up and intelligent. She constantly tried to prove herself. I discovered that she wasn't quite as young as most girls with a fresh R.N. degree, because she was both an L.V.N.⁵ and an R.N. She had decided to continue her schooling after her L.V.N. degree. The school that granted the R.N. wouldn't accept credits from the school that granted the L.V.N., so she ended up going to school for five years. She was considering going on in her schoolwork to become a nursing teacher. She had worked at the County Hospital as an L.V.N. while going to school, and was full of far-fetched tales. Her other favorite topic of conversation was about school, how difficult it was and how she was always in the top of her class. But I guess the older nurses were impressed, since she was on my case for five months, afternoon-evening shift, and was considered the head of my round-the-clock nursing team.

At first she was the only nurse who attempted any communication with me. Between the misinformation she was able to accumulate and her air of utter self-confidence, she was able to impress people. I put up with Rhea because she learned to understand me, and in those days only she and Vic tried. She understood the words, but gave them her own interpretation and wouldn't believe she could be misinterpreting. To me, she was also sort of a symbol. Her hair was the first thing I remembered seeing when I came out of the coma. Her hair and her lectures became almost a way of life that went on forever and ever, until I thought I would spend the rest of my life that way.

Each day I was determined I wouldn't say anything for her to misunderstand. But each day was an eternity, and I wasn't used to not having my say, especially when she said some things to me that I thoroughly disagreed with. So every day ended in a disagreement and a lecture, which I was powerless to turn off. I don't think this was done to make me talk, because we also had regular practice sessions.

I got very dry, even though I was being fed through a gastrostomy⁶ tube, and yelled for water. When Rhea finally understood what I wanted, she told me I could have one to two cc when we were finished. I didn't realize that I had to learn to swallow again and I couldn't understand why I was in a private room and limited for water. But that one to two cc of water was good, when I finally got it. I wanted more, but she refused.

⁵ Licensed Vocational Nurse

⁶ A rubber tube through the abdomen directly into the stomach

After a while my inability to do anything about my frustrations made me very angry, and I yelled more, much as I tried not to. Then I was told I was disturbing other people, so I learned to yell silently; but every once in a while I yelled out loud. I was told I had the only room on that floor with soundproofing on the ceiling. That helped a lot. I figured, “We are paying for it, so why not use it?” And I did.

Rhea made out a schedule for the day which included, among other things, my yelling time. The other two nurses found her schedule and had a good laugh. She may have been trying to preserve her own sanity, but I doubt it.

My first day nurse, Mrs. Olson, was a sweet woman with a darling face and figure and prematurely grey hair. She looked both young and old at the same time. I don't remember her or the two subsequent day nurses ever sitting down very much. The things I do remember connected with her are her putting some plastic boots on my legs and trying to blow them up with her breath. She was very winded from this ordeal but it was her job and, by golly, she was going to do it. These boots were supposed to help reduce the swelling in my legs. She would be blowing them up about the time Vic arrived for a visit. He offered to blow up the boots with her, and she was very grateful and relieved.

I couldn't figure out why I was there in the first place. Secondly, why was he helping the nurse when he always made me do things for myself? I was angry. Then I wanted to ask many questions that I didn't want to ask in front of anyone else but Vic. He always came when the nurses were busy. Soon I found out that I couldn't talk, and was angry that I couldn't express myself. I had never heard of such a thing before and couldn't believe that this was real. Finally, I spelled it out to Vic:

Don't help nurse so much

When I first came out of the coma, my mind still wasn't entirely clear and I wasn't awake for long periods, especially at night. When I was being turned over onto my side I thought I could read the nametags on the nurses' uniforms. Since there were about three nurses on each side, I needed to read the names very quickly, I thought, not realizing that I should be able to read them at a glance. One of these nurses was my first night nurse, and her name was Miss Artese. Every night, when she came on duty I listened to her talk to Rhea, the afternoon nurse. I was convinced that she was really Arlene Ragan, a long-time friend of mine, even though the information I heard about her personal life didn't jibe. But I wasn't going to have anyone that I had previously known taking care of me, especially Arlene, because she was ill herself with an inoperable brain tumor. So I spelled out to Vic:

Fire Arlene

He said, “Do you mean Artese?” I indicated with my eyelids, “Yes.” Vic told me to think about it and he would consider what to do. The next day I got a long convincing lecture from the afternoon nurse, Rhea, to the effect that I should stick to my own decision and get a new night nurse, because this was my decision and no one should influence me. I later discovered that

Miss Artese and Rhea had conflicting personalities.

Meanwhile, Vic discussed my request with the doctor, who recommended doing as I asked to show me I could have an effect on my surroundings. Meanwhile, Rhea told Miss Artese about the whole thing, and she resigned before I had a chance to confirm what I wanted done. I heard later that she was a very good nurse.

My next night nurse, whom I'll call Mrs. Fussy, was also a good nurse, but she made me angry. I would be almost asleep when she breezed in to straighten the covers her way, which they probably needed, and turned the T.V. to an all-night music station, which the nurses mistakenly thought I liked to go to sleep to, all the while crooning in a deep, alto voice. At this time of day my patience was really gone. I tried to tell her to leave me alone, but she went right ahead while I got madder and madder. I wanted to go to sleep because I knew she was going to wake me up at four in the morning, after a sleeping pill at 11, to give me a bath. I later found out this was done to save time for the day nurse and give the night nurse something to do. At the time I thought, "I have heard you have to wash early in the hospital, but this is ridiculous." So the best I could do was spell out to Vic:

*I can't stand Mrs. Fussy---She does things she doesn't have to when I want to sleep---
Pulls sheets---Asks silly questions---Starts soon as everyone leaves---
In the morning she scares me---Different ways---I dream she cuts my legs.*

I was sleepy yesterday but didn't sleep---Just perspired so Mrs. Fussy gave me a bath

One night I had a dream that Mrs. Fussy really knew how to turn patients, and have everything come out all right in the end. While it was happening it was very painful, because it involved cutting my legs into pieces like a jigsaw puzzle and fitting the pieces back together after I was turned. We discovered later that Mrs. Fussy had once cut my toenails during my sleep.

Some of the nightmares I had during this period were still pretty mixed up, but did show some contact with reality. For instance, I thought someone was weighing me down with empty Sego cans with ragged edges. They put them around my neck and I couldn't move for fear of having my neck cut. My neck was irritated by a tracheotomy tube (trake) inserted to help me breathe. I was being fed Sego through a gastrostomy tube that went directly into my stomach. I still bear the surgery scar, though the tube has long since been removed. The family has dubbed it my "belly zipper" and another little round scar as my "spare belly button." I still didn't realize the experiences were dreams, because I spelled out to Vic the next day:

Get Sego cans off my neck

I was told later that involuntary jaw motions were catching my lips between my teeth, causing them to bleed and swell. The nurses tried various techniques to protect my lips, including putting a wet gauze on them. One time a nurse tried to put a rolled-up gauze between my lips and teeth. After a few involuntary chews it started to go back in my mouth. The nurse grabbed it with her fingers just as I chomped down. Ouch! I only remember being told not to bite my lip, and having it pulled out. I thought the people were nuts. In my dreams I always had

a dog's face with a dog-like mouth. And I couldn't understand why they were keeping a wet gauze there.

Another dream can't be related to anything that happened at the hospital, but only to the fact I hadn't seen my children for some time and had no prospect of seeing them in the near future. In the dream I was floating down a river, which suddenly divided into four parts. My body was cut up into four parts, and each part floated down a separate section of the river and never met again. Each part of my body seemed to represent one of my children and I was fighting to keep my body together, but it had to be cut apart in order to be turned because I was too large to be turned in one piece. The next day Vic was a bit shocked by my spelling:

Body cut up

I remember having only one pleasant dream. I was walking around in the kitchen of my house early in the morning getting breakfast and getting children off for school. Then I woke up to stark reality.

After I was conscious for a week or so in the daytime, the dreams at night stopped altogether. Then the nighttime became the best part of each twenty-four hour period. I knew that all my family was asleep and I could go to sleep and forget about practicing something every minute. On the contrary, waking up in the morning was the worst time of day. I was very stiff, plus I had to face horrible things like painful electrical stimulation, range of motion exercises and anything else they could think of that might do some good. Even meals were unpleasant to me, because it meant practicing chewing and swallowing, trying to keep from choking and spluttering anything in front of me. That's quite an experience for someone who normally loves to eat.

I wasn't quite clear headed enough to realize that they were only trying to help me. To me, it was just pure torture that I was forced to go through against my will, and I was determined to show them that they couldn't hurt me with their torture and then they would get bored with it all and stop.

Sometime early in the Scripps episode the man with the instant positive pressure machine (inhalation therapist) came in to give me a treatment. I decided he was my friend. He had come to sweep all the hiding visitors out of my room, since he could detect them easily with the machine. I thought there was a balcony where people could see me. But this was not close enough for my family and they were hiding all over my room. Naturally, Mother was in the bathroom and some people were hiding behind the white curtains that go around the beds and many other places in the room, but the man with the machine flushed them all out. One time, I could see my oldest son, Larry, running up to the outside of my window. My mother was trying to keep him away and I was frantically trying to tell her to let him come in. It didn't seem to register on me that I was on the fifth floor.

Sometimes I must have slipped back into dreams in the daytime, because I remember Rhea lecturing me about sleeping during work time and staying awake at night. I also thought I had to spend the mornings in a room where the electrical impulses were channeled into a large circle. I flew around with the electricity and it hurt like fury, but the nurses kept telling me I had

to stand this and then I could sit up and walk. Later on I found an electrical stimulation machine in my room that was seldom used and finally taken away. My physical therapist admitted that she couldn't stand those things either, so it took a lot of blind faith later on at another hospital to let them put it in my mouth.

Of course, Vic told me that my operation had caused brain damage, but it was like a bad dream. This couldn't be happening to me. I had too much to do to waste time staying in bed. He also told me that I wouldn't be active for a long time. What he told me, I understood. But I had never thought much about it happening to me, and it took a while for the truth to sink into reality. This was the kind of thing you read about in the newspaper, but it doesn't happen to you or anyone close to you.

At least the ability to communicate with Vic by spelling out words was helpful. I told him of my worries:

*I am a freak
I'm afraid of future*

Some of my dreams produced strange questions:

*Do I have vagina
Why do I have rubber hands in mouth
Hat clamps hurt me
They did rectal tube: I hear nurse say I have rectal tube*

I could tell him about my discomforts:

*Toe was bent in slipper---it hurt
Bottom arm twisted
My hands and feet are too squashed*

And my hopes:

*I want to go home
Go where there are no people*

And I passed on to him my feelings and fears:

*Other girl---Do you have other girls?
Dream you had other girls
I love you
I'm afraid I won't wake up
How long will you love me when I'm like this
I don't like being a vegetable
I'm only first wife*

But it was still very frustrating:

*You won't listen to me
Why can't I talk lots---Not spelling
Nobody can understand me—Not even you
I get frustrated because everyone goes so fast and leaves me hanging in my*

thoughts

MY 'PLUMBING' PROBLEMS

A lot of things had to be done to keep me healthy and to help me recover some motion. At first, in Oregon, it was a matter of survival. A tracheotomy tube was installed in my neck to help me breathe (nicknamed the “trake”). Since I couldn't swallow, fluid had been building up in my throat, causing a gurgling sound and making it difficult to breathe.

Then there was a three-times-a-day treatment with a positive-pressure breathing machine to help clear my lungs. Otherwise, my lying stationary all the time would allow pockets of fluid to build up in my lungs, leading to pneumonia.

The first day or two I was fed intravenously. Then the doctors switched to a tube going up my nose and down to my stomach. When it began to look like a long recovery, they inserted a gastrostomy tube directly through my abdomen into my stomach.

Of course, they also had a catheter in my bladder to drain the urine. With all this plumbing in me, the chances of infection were pretty good, so they gave me regular injections of antibiotics.

All of the time I was in Scripps Hospital I felt very hot and the sheets were changed many times a day because they were wet from perspiration. At first my temperature went up and down for no reason at all. They took my temperature and blood pressure several times a day. For the blood pressure, they always said “good.” But they never could understand the temperature, so they gradually stopped taking it. This made me very happy. Even the little pressure from the armband or the rectal thermometer was quite painful to me. The whiff of the blood pressure gadget reminded me of the many dogs in my dreams. Later, I didn't have a temperature, but still was swollen and warm, so the nurses let air into the room as much as possible.

One day Mrs. Olson, the gray-haired day nurse, made a big production of having Rhea take her blood pressure in my presence, and do something that sounded like a wooden leg was coming off. The next day, Mrs. Olson told me as she left that she was leaving the case because she was tired and needed a rest. I thought it was reasonable, since it was a seven-day-a-week task and I was a very hard case for special nurses.

But I wondered why the big production the day before. I found out later that they were trying to soften me up for the news, because Mrs. Olson had been instructed to tell me herself that she was quitting the case. She wanted me to really believe her reason, but she was reluctant to tell me. I couldn't see very well at that time so I never figured out what the sound of the

falling hardware was.

The next day was miserable for both me and the new day nurse, Angie, but we later turned out to be good friends. She was very funny and a good nurse. I was at a stage where I greatly appreciated both characteristics. She was of Italian descent and was always telling me in an Italian accent what “Mama” said, or how “Mama” brought up her large family of children practically single-handed, because “Papa” was always at his pharmacy. The first three of the children were from “Papa’s” first marriage. Angie was considering following in her mother’s footsteps by marrying a doctor with three children. She made funny faces at me and started my tongue moving. At first I could move it only as far as my bottom lip. Now, it’ll go about two-thirds of the way to my chin and cover only my top lip. Before the accident it could reach my nose.

At first, Angie didn’t give me much confidence in her ability. The first day with her was bad for both of us. I heard her muttering under her breath for strength to get through the day. I thought she was a flibbertigibbet that didn’t know which side was up, but I was powerless to do anything about it, so I gritted my teeth and hung on for her sake. When it came to lifting me out of bed the nurse on the case usually took my head to keep it straight with my body. The first time I was moved with Angie helping I thought, “This is the end,” but found out that we got through it all right. I was too scared to complain and she turned out to have more sense than she at first exhibited. We became good friends in no time and I could hardly wait for her to come at 7:00 a.m.

My hair hadn’t been washed since the accident: it was only cut off butch style after I had two sets of holes drilled in my head for Crutchfield Tongs in traction, and had a decubitus (bed sore) on the back of my head. So Angie decided to give me my first shampoo in months. My sister, Dot, who was staying at my house at the time, came to help her. They lifted me onto a chair that flattened out, and pulled me up high so they could wash my hair over the sink. One held up my head and the other scrubbed. I felt fairly safe with them on either side of me, but I was relieved when they were finished. This happened every week in some form or other until Angie left.

Soon I was put on baby food instead of being fed and medicated through the tube into my stomach. I thought I was doing quite well, but suddenly I was taken off the baby food and put back on the tube. That was very discouraging to me, because I thought I was going backwards. I found out later that the three nurses were worried about some funny wheezing noise I made when having a bowel movement. For some reason they thought it was connected with my having the baby food. I’m still making the wheezing noises.

I don’t remember what was done about bowel movements before Angie came, but she introduced me to the world of suppositories. She was a firm believer in a good cleaning out. Sometimes I wonder if she wasn’t too firm, because once in a while I was only sitting up in bed and things happened. Very, very demoralizing. I once asked Rhea if I could take a pill instead of what she called a black and white cocktail (cascara and milk of magnesia), because it tasted so awful and I always got it on the sheets. She told me, “No.” Now I know that isn’t true.

I had lots of laughs with Angie. She was in general a hilarious but very sincere person. She said a lot of crazy, unprintable things. Just about everything she said came out in a funny, but not offensive, way. A lot of people, especially the aides, get very vulgar after working around a hospital for a time. And all you can do is laugh, cry or be a poker face. I elected to laugh, since that seemed to be the wisest choice. Those who aren't very intelligent thought I was laughing with them: the more intelligent wondered if I was laughing with them or at them. That's the beauty of not talking: it always keeps them wondering.

Angie would make play out of her work. I remember one time when I was supposed to practice blowing. The hospital had individually wrapped straws. She tore one end off the paper, pulled a little of the straw out, stuck it in my mouth and told me to blow the paper off. I blew and nothing happened. Then we started to giggle with the darned straw still in my mouth. When I laughed my diaphragm bounced and the paper flew off. We had papers from straws all over the room. Then we laughed because two grown women were acting worse than children, and more papers flew. Every time I got one off she stuck another one in my mouth. It got to be worse than a circus. Laughing is supposed to be good exercise for the diaphragm. I guess she figured that even uncontrolled exercise was better than none. Or maybe I was supposed to first get the feel of bouncing the diaphragm in an uncontrolled manner, and then do it under control. I'm still laughing very easily at anything funny, and I'm still trying to bounce my diaphragm purposely.

Sometimes adults think children use an ordinary accomplishment, such as learning to blow, as a way to get attention. But when a child first learns to blow out a candle or blow up a balloon it must seem to the child that he has accomplished the impossible and he wants to tell the world about it. The child doesn't know what may be on the adult's mind. He can only think about one thing at that instant. The thing that is most important to him at that time is his accomplishment. So he interrupts anything else going on. The adult may easily construe this to be a thoughtless child looking for attention.

Then there was the time when I was learning to drink through a straw. I could do it with no distractions, but it took over an hour to drink a glassful. This day my mother and her husband, Bill, and a couple who were their good friends came to visit. The nurse put in a full day without stopping for visitors, so she kept on working, sending the visitors out of the room whenever she needed to. But drinking a glassful through a straw seemed like something I should be able to do with visitors in the room. But it was just like learning to sip all over again. Nothing came up through the straw, no matter how hard I tried. So the visitors start acting like a bunch of cheerleaders trying to spur me on to suck up the glass of juice. They all started to show me how to do it. Then Angie and I got so tickled at the way they were acting that she could hardly hold the glass and straw. I had a hard time doing something which usually is very simple. I was trying not to laugh and not to cough while trying to suck up the crazy glass of juice. It sounds easy but was a difficult thing for me to do, and I was relieved when no one was watching any more.

I was supposed to have inhalation therapy treatments four times a day. Quite often Angie turned down treatment number one or two, because she was too busy. The therapist would walk in unannounced with his machine and his ego sticking out. Angie couldn't stand him. At first she told him to leave the machine for her to give me the treatment later. Then she felt that she

was doing his work. She couldn't stand that because of the clash in their personalities. This fellow had an ego that showed, but he was very funny and very strong. Later, the third day nurse, who was a little older than Angie, ignored his ego but used his funny nature and his strength to her advantage. Instead of goofing off, he was giving me the treatments, acting as an orderly for me and keeping me cheerful.

After I had been on the baby food for a while the second time, Angie assisted a surgeon in removing the gastrostomy tube from my stomach. This time I was really scared. I would have held very still even if I wasn't paralyzed. But it was all over within a very few minutes and I felt no pain. The doctor left a rubber stopper but it wasn't even needed. Thank goodness, I healed up quickly. The nurse showed me the horrible looking tube that had been in me for so many months. It looked horribly big. Formerly it would have made me sick, but nothing seemed to faze me now.

When Rhea found the tube gone in the afternoon she was disappointed, but resigned to it. Her idea was to give medication through the tube and food through the mouth, even though I had been given medication by mouth before. She also wanted to use it as a safety feature. Angie felt that with it gone, food and medicine would have to go in through my mouth. I guess the doctors must have agreed with her. I was glad to be rid of the extra appendage.

A few days later the doctors agreed to removing the trake for an hour or so. I had been complaining of a sore throat, but they couldn't see any reason for that. It felt like swallowing was being irritated by the trake, but since the windpipe is not connected to the throat it took many conferences before the doctors agreed that this was possible. When a trake had been in for as long as mine had, the tissue was reported to stay open for 24 hours. Mine was out for an hour or two. When Angie tried to put it back in, the opening had already started to close up. She sent for a smaller size, but still couldn't get it into the opening that was left. This did hurt: the pressure of her trying to push that thing into a hole that was too small was pretty great. But I didn't notice too much, because I knew Angie's personality. I thought she wanted the darn thing out anyway. And so the trake was removed permanently. Her predicament seemed rather funny. I couldn't decide whether she did it on purpose, or whether she had been instructed to remove it and was putting on this show for my benefit. I knew she would try anything, but she was also a good nurse. She was either caught in her own trap, or she had orders and was putting on a good show. Anyway, I wasn't bothered with cleaning and dressing the trake anymore.

My external plumbing (catheter) was very uncomfortable and kept getting almost stopped up. The nurses changed it every day for several days in an effort to clear up the difficulty. I had used catheters after previous surgery. They were very uncomfortable for me. I always had them taken out as soon as possible and immediately went to the bathroom on my own. But I had never before been conscious when they put the darned things in. Now I had to submit to having one put in every day by a redheaded nurse, who not only had the upper hand but was a person with whom I violently disagreed on many subjects. She said, "The other nurses asked me to do it because I have been on the case longer and June has more confidence in me." But I think they wanted her to do some work. Try as I would not to mind, I always ended up screaming.

Changing it didn't help, so a day or so after the tube to the stomach was removed, the

doctor strode in and said, "Take it out altogether." Both Rhea and I were very surprised, and she must have shown it. I'm sure I would have also, if my new poker face would have let me. The doctor must have realized her surprise, because he explained, "June is so strong she can take anything."

So I lost my enemy, the catheter. Rhea was angry because she had no warning and had wanted to bladder train me. But I had worn the dumb thing for more than four months and I was glad to be rid of it, even though I lived in terrible fear of wetting the bed. Vic had told me I would have to learn everything over again, but the idea of a wet bed for an adult appalled me. I had learned to make a few sounds, but nothing would come out when I tried to say, "Pan," since "p" seems to be a particularly difficult letter.

I had the problem of knowing when I really must urinate. Sometimes I thought I had to go, but when I was put on the pan I just couldn't. That's a silly thing to be worried about. Normally, I would never have given it a second thought. When I was well I urinated once in the morning, once at night and once during the day when nature called, and that was it.

Now I could only tell a few seconds ahead of time and had to make known what I wanted. Sometimes I couldn't make the nurses understand, and try as I might, I couldn't hold it in. It just happened. Other times, I forgot about the problem and while laughing about something entirely different, whoops, without any notice I got all wet. Other times I could sit on the darned, hard, cold bedpan and think of running water, warm wet feet, stare at a corner of the ceiling, press on a spot on my stomach, etc. and still couldn't let go a drop. This was a problem I never dreamed of having. It caused much consternation and embarrassment on my part. As a shy 38-year-old adult you aren't in the habit of telling someone when you want to go to the bathroom. Now they can't even understand you when you do tell them. Once they get the picture it's funny to watch them fly to help you. Sometimes they are in time, sometimes not.

NEW COMMUNICATION SKILLS

When my mind suddenly cleared six weeks after surgery, I had to cope with two big problems. The first was how to communicate. Vic started spelling with me: I blinked my eyes when he said the letter I wanted. Some of the nurses picked up the method, too, but it was very slow and was often misunderstood. Slowly, during the next six months, I learned to form letters and words with my lips.

After people started spelling, with me indicating yes or no, I became very frustrated by several different problems, and in the process learned a lot about our difficult English language. At first I tried to spell as I would talk. But there is not enough time for that. Also, people come to what they think is the logical stopping place in my sentence and stop before I'm finished. This usually completely changes the meaning of what I'm saying. No matter what I did, I couldn't make them understand that I wasn't finished. So after much frustration I learned to construct sentences so that the subject is the last word. I had to pick and choose my words very carefully to use the least number of words possible. Signaling was a very exhausting experience. You can't imagine how tiring just opening your eyes can be, especially when you are forcing them open when they are stinging with tears that just seem to come at any time. That was when

the tear ducts started to function again.

For a long time, when a good part of the day was taken up by yelling and crying, my tear ducts didn't function at all. When they finally started to operate, I had to do the unnatural thing and force my eyes open to signal, "Yes", but this let the stinging tear right in on the eyeball. I was unable to wipe the tear away myself. If I asked to have it done the person spelling with me lost their train of thought. I had to open my eyes anyway to ask to be wiped. Meanwhile, both I and the person trying to understand became utterly frustrated.

To communicate by the slow spelling method I was forced to become very patient, and to develop a good memory. I had to remember both the sentence, which took forever to get across, plus which letter of which word was understood last. Sometimes I knew where I was, but was mistaken about what other people had understood. Then they got the wrong information, which was almost impossible to cancel. It was very difficult to find out what information the other persons had obtained. If they repeated the words they knew, I felt very fortunate, because most people didn't realize that I didn't know where they were. They were eager to find out the rest of the information.

Another problem I had, because of having to put the subject at the end of a sentence, was that people, especially my overburdened husband, would come right up to the last word of my sentence and then tell me that there wasn't time to finish. They could find out later, which they almost never did. I didn't have the energy to spell this all over again. Unless of the utmost importance, the subject was lost forever, or I found out what I wanted to know after it was too late to change the course of history. I usually found out by listening to other conversations. I might be called on to know what they were talking about.

I will say this for Rhea; she was the only nurse who felt brave enough to leave Vic and me alone for a little while, even though all the nurses knew that Vic had acted as my nurse in Oregon for two shifts a day. Her philosophy seemed to be to train me in the same way she would train a baby, even though I was a grown woman with some sense. Sometimes I was so frustrated with her talking constantly and very fast and telling Vic that what she said was my attitude also, that all I could do was scream. Of course, I knew I was defeating my own purpose, and then I grew angry because it was so difficult to get my own points across. Then I started laughing at the ridiculous situation I was in and that would convince Rhea that she had won a point.

Report time, which occurred three times a day, was a terrible time of day for me. In the first place, I knew nothing at all about nursing and didn't know that giving a report when changing shifts was regular practice. In the condition I was in, it seemed to me that whenever they wanted to talk about something they didn't want me to hear it would conveniently be time for report. So, the nurses would excuse themselves from the room to give each other their opinions and ideas about me, which they considered to be gospel truth, but was usually misconceived. I knew many things were misconceived, because to stay sane the nurses quite often talked to themselves in the room and voiced their opinion of many things that happened involving me. Since I couldn't talk, I had no way of telling the nurses my opinion or feelings about various situations, or what a situation really was. I'm positive that many a report would have been very different if there had been better communication between this patient and the

nurses.

My situation did help to increase my hearing and awareness. I got very tired of always practicing, practicing, practicing, and would listen to the noises in the hall. Gradually, I could hear more and more. This was at times very frustrating, as well as rewarding. For example, there might be a couple of people in my room engaged in conversation when there came a light tapping at the closed door. I heard it, but the other people didn't; I couldn't answer the door; I couldn't tell the other people to answer the door. By this time I could squeak, but if I did the people construed it to mean that something was wrong with me. So I had to learn to be more patient and wait for a louder knock. It took a long time to face the fact that if I did anything the situation became more difficult.

I became used to false information going into the nurses' reports, but I never got used to the false information given to my husband. If I laughed about it because I couldn't give my opinion they construed it as agreement. If I cried because I was unable to state my opinion, I threw more false information to the winds. All kinds of interpretations except the one I had in mind were inferred from the act of crying. I couldn't tell from the continual genial expression on Vic's face whether he believed what the nurses were telling him about me. Their medical facts were correct, or at least I had no basis for argument, but when they got on a personal kick and started explaining why I was laughing or crying or making queer noises I became perturbed. I had no way of finding out whether or not he believed all this foolishness. I knew that Vic understood my feelings better than anyone else did, but I couldn't talk to reassure myself. I began to wonder whether this barrage of misinformation was beginning to make some headway. I was thinking all kinds of thoughts, some true, some my own conjecture, but the expressions didn't show up in my face, or even in my eyes, as people say they do now.

Finally, I had the chance to spell out to Vic some of my feelings:

She asks me questions then doesn't wait for answers---Today she asked do you want the pan---I said yes and she did and I did

Lots of questions misunderstood---They tell you only one side of the story.

Rhea believes in rest---Don't believe my eyes---I want to keep them open---She does make me rest.

I have to listen to her lecture me.

Don't say anything to Rhea---She is doing better.

PHYSICAL THERAPY

The next step was physical therapy. Joints that are not moved regularly become very stiff and sore as they build up calcium deposits. The solution is regular range-of-motion exercises, whereby each joint is moved a few times to its maximum extent. Of course, by the time they started this with me the joints were already pretty stiff and sore, so I screamed. In Oregon, the doctor showed Vic how to do the exercises with my arms and legs. They really worked seriously on them at Scripps. The head of the Physical Therapy (PT) Department used to come up to my room to give me the range of motion exercises. She also tried electrical stimulation for the muscles to restore some motion. I cried when I saw her coming, not only because she hurt me,

but also because her hair was red and I had her confused with the afternoon nurse. I guess I hurt her feelings, because soon she sent a pretty, very sweet, dark haired girl to replace herself. With this girl, I learned to grit my teeth and stand the pain. At first it hurt when my arms were raised even a few inches, but each day they went up a little bit more. I was always disappointed that I couldn't move myself after standing all that pain. She got my arms so she would hold them way back without hurting and taught me to have some use of my left arm up to the elbow.

When the P.T. exercises started, my mind was still fuzzy. I dreaded the times when my knees were bent and my legs went up in the air, because I was convinced they would break off at the hip joint. I also thought I had many, many legs and only two of them were being exercised, the main two. I was always relieved when my legs were back on the bed, but disappointed that I had gone through all this fear and nothing miraculous had happened. I could only look forward to the same the next day. To me, the P.T. Department seemed to be helping me to get out of that place and go home. Even though I was afraid of what they would do to me, I wanted them to hurry up and get it over. But they only stayed a short time each day and I put my hopes on the tomorrow which seemed never to come.

I remember forcing my eyes open for the doctor while he aimed his little light in them and asked me to look to the left, right, up and down. I tried my darnedest to follow his directions, but my eyes only moved a very little. He was very gentle and complimentary and told me how well I did. It was during this period that I was really confused about directions. To test me everyone was telling me that left was right and vice versa, and I believed them beyond a shadow of a doubt. So I don't know if I was trying to move my eyes in the correct direction or not. I think it was Rhea who finally let the cat out of the bag and told me I was being tested and straightened me out about directions. I felt very foolish, but angry, when I found out I had been tricked.

At Scripps I became aware of the regular process of turning me from my back to one side and the other. No matter which part of me hurt most, it was invariably the last part to be touched during the turning procedure. Try as I might I couldn't find a way to indicate my distress. In fact, I found it was faster to wait out the pain until the nurses moved the painful part, than to try to make them understand. But, being the keep-trying kind, it took a long time to get this through my head. Meanwhile, I yelled because I had to express myself in some manner. That was the only sound I could make, and it was erratic.

But how were the nurses to know of my frustrations or do anything about them? I didn't realize it at the time, but my malady is rather unusual, and they were only human. I was placed in three positions for three hours at a time. It's impossible for me to stay for three hours in one place without moving a muscle and not ache bad enough to cry, even now.

I finally got it across to Vic that I couldn't take it that long lying on my sides. He must have asked that they turn me more frequently, because after that they reduced the time. Also, by this time my tolerance had built up so that I could stay in one position about an hour and a half. Then they rearranged my legs, which was nice but made me feel like I was hanging by my feet. Also, I got the story about how big I was and how they had a difficult time getting help to move me. That was great for my morale. Here I was in this place I despised, at the mercy of these

strange people who told me I was too big to move. I wondered what would happen to me if I were heavier. I guess I would still be yelling and they would still be ignoring me.

After I had been at Scripps some weeks it was decided that I should sit up in a special blue chair that flattened into a bed. A man came up to show the nurses how to put me into the chair. It took four or five nurses to do the job. They stood on one side of the bed, decided which sheet they were going under, and wiggled their arms underneath me and the proper sheet. Then at the count of three they all lifted, pivoted around and put me lying in the flattened chair.

I had some breathless rides and always closed my eyes while airborne. I was always happy to have Vic or a tall, strong black man from the P.T. Department helping. I felt much safer then. This was before I ever heard of such a thing as a hydraulic lift. I suppose the doctors wanted it done by hand, because I was still wearing a hideous brace on my neck and my head had to be kept absolutely straight. When I was placed on the chair flat I had the feeling that my head was falling off the chair. Most of the nurses kept one of the borrowed private duty nurses to stand by my head until they were ready to put the chair up. But Rhea felt herself competent in psychology and she told the others she didn't need any more help. I was scared to death and started to scream without control, so she sat down and told me she wouldn't move until I was quiet.

I was supposed to get up in that chair twice a day for as long as I could tolerate it - once on the day shift and once on the afternoon shift. But after a while Rhea decided it was just too hard for her to get help, and I needed the rest anyway. Rest? That's all I got in the afternoons.

Later the P.T. Department and nurses decided I should practice sitting up on the edge of the bed. Getting me up into this position was quite a process and very painful. But it was more painful to lie in one position most of the time. By now even the nurses were reluctant to make me lie on my side, because I made such a fuss about it. It finally got to the point where they did it only once a shift, and only a little longer than I could stand it. They said they could get away with it now, because I was going up and down in the bed and getting into the chair, so I wasn't continuously lying flat.

Dangling was what they called sitting up on the edge of the bed. I was sure that I could sit up once I got up. It was really a shock to find that I had lost all my sense of balance and felt like a bony, shaky, rag doll. It was easy for Vic or the nurses to hold me up, but I felt very uneasy until I was safely back on the bed. I stayed up for about 45 minutes with Vic sitting next to me. At first I'd try to balance, but the last few minutes I leaned against Vic.

I was glad they tried it at first only when Vic was around. The hard floor seemed a long way down and I really didn't trust the nurses. After a while the P.T. girl and Angie tried it together. At this point I was apprehensive but went through with it. Eventually, I let Angie do it by herself. She was a little bit of a girl but very confident and ready to try anything. She did the arm exercises while I was sitting up on the bed. It hurt like mad but to get to where I could do things myself was worth it, I kept telling myself as I gritted my teeth to bear the pain in my shoulders.

One of the nurses couldn't understand why I was not having a problem with saliva. As soon as I tried sitting up the problem was with me. The nurses were really kept busy mopping up while I was in a sitting position. (This problem has now lessened somewhat. I still have some trouble when doing tongue exercises and when trying to talk. I have learned to swallow most of the saliva, but still cough on it once in a while. When a spontaneous laugh arrives all those in my range get a free shower.)

One day, when the P.T. girl came up, she announced that they were going to try standing me on my feet in a few days. First they had to work out the logistics of help, etc. This became the focal point in my thinking. I had my mind made up that I would soon be walking. Why I thought this, when I couldn't even balance sitting up, I don't know. I knew it would be a hard thing to do but I was sure I could do it in a little time. It was a great shock to me to find out that this was going to take more time than I had anticipated. I had to get out of there and back to my family. After all, school had already started and my sister, who was taking care of my home, had to go home soon.

When they finally tried to stand me up, I was frustrated at every turn. It took one strong man in front of me holding back my shoulders, and three girls, one of them on each side to keep my knees from buckling, and the third in back pushing on my rump to hold me up. This was all done in the P.T. Department next to the parallel bars with a mirror (full length) along the length of the bars. Here was the first good look I had at myself. Even with my bleary eyes I could see how awful I looked. Why someone would bother with me I couldn't imagine, and yet here I was, perfectly helpless but yet alive, and of no use to anyone, and people were trying to make me whole again. The whole realization was very hard for me to comprehend.

I then traveled to the PT. Department every day in the big blue chair to stand. Having no balance made me very uneasy. Even though the blue chair looked very sturdy, I felt as if I were turning over in it either backwards or sideways. Going around corners in the hallway of the hospital, especially when we were a little late going to the P.T. Department, always made me feel as if I were falling over sideways.

I tried my darnedest not to make a scene in the hallway, so that by the time I got to the P.T. Department my nerves were really jangling, tranquilizer or not. Fortunately, I was usually scheduled for a time when no other patients were in the department. It took almost the whole department to handle me, and the few who were not needed for me were giving treatments to other patients in their rooms.

So the people who stood me up were accustomed to my being upset; only they had no idea what in the world was the matter with me. I must admit my behavior and the reasons behind it were rather unconventional. My fears were not limited to just one thing, so that the people working with me not only were wrong once with each guess, but many times. Each time I got more upset, because I was not accustomed to this no-voice business and was very frustrated when people couldn't understand what I was trying to say. Communication is bad enough when you are able to use words, but I was trying to play charades without talking or moving.

By this time I could tell the difference between the afternoon nurse, Rhea, and the head of

the P.T. Department. But also by this time the therapist was convinced that something about her appearance made me upset, and then I got angry because I couldn't explain to her that for a while I had thought she was someone else. I later learned that other people thought the two redheads were sisters and that it made her very upset.

When I first went down to stand up I had a brace put on my right leg. My leg had to be stretched out straight from a sitting position. I had no idea that stretching out my leg from this position would be so painful. It was as bad as the pain in my shoulders when my arms were lifted, only it was along the whole leg. Between the ride that was frightening to me, and the pain in putting on the brace, I was in great shape for standing up. Yet I waited each day for this to happen.

Standing me up was quite a process. They first pulled me close to the edge of the chair and then pulled me up to my feet and adjusted my body to the proper standing position. Since my right leg was braced, it stuck out at a peculiar angle while I was getting up. Next they had the problem of placing this leg underneath the rest of my body and getting my hips in the proper position for standing. I was frightened during this process, but yet I wanted the practice so that I could stand and walk by myself.

At first, when they asked me if I was tired of standing, it hadn't crossed my mind to be tired. I thought I was to stand up there a certain amount of time and then they would put me back in the safety of the chair. So at first when they asked me if I was tired, I said, "No." Later I realized that perhaps they were growing tired of holding this big girl up. I was in a quandary. I didn't want to make anyone tired beyond the call of duty, but yet I knew I must have help to practice, and I am not an ordinary size.

During the first of these visits I still had a catheter for urination. One day it had been clamped off for a while and there wasn't time to drain it before we were due at the PT. Department. So, when we got there, Angie looked around for something to drain it into and all she could find was a man's urinal. So there we were, draining a catheter tube coming out of my pajama bottoms into a man's urinal, and hoping that the man who usually held my shoulders wouldn't arrive for a few minutes. We made it, but we were still giggling when he arrived. They say laughter and tears are not very far apart. On my part the difference is minute and the poor man thought I was crying again. Fortunately, some of the girls told him I was laughing, but not to ask questions. He was happy with the explanation and added a few funny remarks of his own.

Angie used to put makeup, including mascara (which was a first for me) on me before we went down to the P.T. Department each day. Invariably when I stood up my head fell forward and I got lipstick on the white hospital coat of the tall black man who held back my shoulders. Everyone thought it was a wonderful subject to tease me about, saying such things as, "What will his wife think when he goes home tonight?" The tall man, after I was standing up stood there very nonchalantly, with all his weight on one foot and the other leg crossed over in a devil-may-care attitude. He would turn his head as if he were pretending that I was standing up there alone. If I started to topple he could feel it and hold me up.

From my vantage point this was most frightening. Going from being able to stand and walk with ease to having to depend on four other people, even though I knew they were capable and responsible, was rather an eerie feeling. I was five feet eleven inches, but when I stood up I felt about an inch taller than the man who held my shoulders, and he claims to be 6 feet even. Could it be that between the surgery and traction they stretched me? But it doesn't matter when I have much greater problems to worry about.

I could hold myself up fairly well from the waist up if I concentrated very hard. But the minute I was reminded to try and lock my knees or pull in on the bottom muscles (which seem to be very important to standing), I forgot all about having to concentrate on holding the top half of me up and started to topple. Most people think of the part of the body from the waist to the shoulders as being held in a straight line by the backbone, but I felt as if my back was in two sections and they never seemed to be in a straight line.

Two times they tried walking me down to the end of the parallel bars, turning me around, walking me back to my chair, turning me around again, and finally sitting me back in the chair, where I felt safe but useless. The walking procedure was scary enough but the turning process was positively frightening. Although I wanted in the worst way to practice walking. I still had an instinct that I couldn't overcome to preserve what was left of me. I was sure that I would be dropped on the hard cement floor. Even though my mind knew that I was in competent hands, I couldn't convince myself to be calm.

So I waited all day and all night for those seventeen minutes and then was as nervous as a caged wildcat while trying to balance and remember to pull in the proper muscles in many different places. I have heard that it's impossible to concentrate hard on more than one thing at a time, but now I really know what that means. It took all my concentration to pull in on one set of muscles; then as soon as I thought about pulling in on another set of muscles the first set was forgotten and went limp.

None of them moved much, so while I pulled with all my strength, the therapist had to feel the particular muscle, to see whether or not it was moving. While the therapists moved my legs and held me erect, my arms also had to be adjusted on the parallel bars. My right hand was the last to be adjusted and always ended up hurting the most, because it was invariably turned the wrong way with a lot of body weight on it.

The turning-around process was the real fright. Not only for me, I'm sure, but also for the people who were holding me up. I was in between parallel bars that were designed for one person to walk between. But there were three people in between the bars and two people on the outside, all trying to coordinate the different parts of my body. I was trying to help, but by the time I reached the end of the bars and it was time to turn, I was completely worn out. I still had to make it all the way back to the beginning and turn around once more in order to sit down in the big blue chair. After two times I'm afraid they realized that they were practically dragging me between the bars.

It seemed strange to me that I formerly fairly flew around the house until all hours, and suddenly I couldn't go on my own power and became exhausted with others doing most of the

work. I watched all the people walking around the hospital and thought how easy it looked and wondered why I was having such a difficult time.

After a while the exercises in bed and the standing sessions down in the P.T. Department were cancelled. In their place I had a session first thing in the morning on the PT. Department mat, and a session in the afternoon down in P.T. in the wheelchair. The tall black man, who previously had been part of the standing team, lifted me on to the mat in the morning. I had the problem of getting my breasts squashed, but it only lasted for a few seconds and standing that pain seemed better to me than the embarrassment of telling him what was wrong. Besides I couldn't say anything if I wanted to.

The therapist then put pillows under my knees and weights on my ankles. With superhuman effort I managed to raise my legs, one at a time, a few inches off the mat. The weights were small, one or two pounds, but they felt as though they weighed a ton or more. I practiced this a few times increasing the weight by a little each day. I had to count out loud as I did each exercise. I think I made it up to somewhere in the thirties. My counting was unintelligible, but I could make noises when lying down, which was an improvement over the time when I couldn't make any sound at all. Then the therapist gave my arms a going over.

When we first started the exercises in bed in my hospital room, I cried with pain. Now on the mat the therapist could raise my arms clear up above my head to what she called a normal position with pain in the shoulders only when my arms were almost all the way up.

While I was still on my back on the mat the therapist placed my knees up, with my feet on the mat, and told me to tighten up the bottom muscles as if I were going to raise my hips. The muscles were so weak that the therapist had to feel to tell if the muscles were working. She assured me she could feel a twinge as I pulled with all my might, but my hips didn't move a smidgeon. Talk about lead in your pants; that is a very good description. It felt as if some of the lead bricks Vic used in graduate school were holding me down.

After a good session on my back she tucked my hand down under my hip and rolled me over my arm onto my stomach. My arm hurt like fury while the dead weight of my whole body was on it, but it was only for a few seconds and soon forgotten compared to the way it felt when I was on my stomach. My neck arched, and the weight of my own head created more friction than I could manage, even though I was able to turn my head when on my back.

After what seemed like an eternity, although in reality it was only a few seconds, the therapist put a pillow under my head. Then things really began to get complicated. I had the problem of turning my head far enough to free my nose for breathing. Since I was unable to hold my breath, I just breathed into the pillow. About the time I felt suffocated, my head was turned so I could breathe, thus stretching my neck painfully. My instinct was to pull my head back, but it wouldn't budge. About this time I discovered that the raised scar on my stomach, or keloid as it's called, was hurting like crazy. Through all this I was expected "to control my temper," which I didn't know existed.

Then, with all this going on, the therapist told me to try to pull a leg up from the knee

while showing me where the appropriate muscle was located. I don't think I could have spoken even if it had been possible.

But this was not the end of each daily mat experience. Next, after trying to lift each leg a few times, my arms were arranged so that I could push myself over onto my back. This was done several times. Each time I pushed myself over onto my back, the therapist rolled me again onto my stomach, or in a prone position, as it is called. Each time I rolled all my dead weight was for a moment on my arm, which hurt very badly. But I soon learned that it was better to be quiet and take the pain than it was to have people concerned and trying to find out what was the matter with me. The pain was great but lasted only a short time.

After this was over I was set up by the nurse and the therapist. Sitting on the edge of the mat, I tried to lift my foot up in a kick and practiced trying to balance in a sitting position while waiting for the man to lift me back into the chair.

All this took only about a half hour. Afterwards I felt exhausted. I couldn't understand why I was so tired after so short a time so early in the morning. I've never figured out whether they stopped the standing because it was too much for me or for them. At the time I felt that it was quite an insult to be changing procedures when I hadn't mastered it yet. Now I realize that they hadn't had experience with anyone in as bad condition as I was in, so they were groping for the best thing to try first.

After the trial of being put back in the chair was over, the nurse wrapped me up and we went out into the fresh air to watch the birds and planes and sit peacefully. Or we took a short walk to find out what was new around the hospital. One time, for some reason, Rhea came on duty while the other nurse and I were still outside. She asked, "Would you like to take a little walk before going in?" I consented, not knowing what lay ahead. We started out and everything was fine. Then she announced that she was too short to see where she was going over the top of the chair, so it would be better to go down the middle of the very little used road in the back of the hospital. The only trouble was that I could see the chair heading straight for some gratings in the road. The direction the gratings were going was the same way as the chair and the open spaces were about the same width as the wheels. And there I sat with no voice but with a good idea that disaster was imminent.

Well, we hit the grating with a bump but, fortunately, not quite straight. "Oh," the nurse said glibly, "I forgot those were there. I'm glad I wasn't going quite straight. I don't think I could pick you up alone."

I must confess that at that point I wasn't thinking about whether or not I was too much for her to handle, and the consequences thereof. We continued on our journey, but what I didn't know was that up ahead the road became very steep, and was much longer than I had expected it to be. The nurse had driven on the road, but hadn't walked there before. I think the walk pushing me was more than she had bargained for. She was panting very hard and needed to rest when we came to a flat spot at the top of the hill.

While I'm typing this now, the ride sounds pretty innocuous, but at the time it seemed

harrowing. There I was being pushed up a fairly steep hill by a small girl, who by her own admission couldn't see over the top of the chair. I felt that at any time I might start rolling backward down the hill alone and I was powerless to do anything about it. Quite a different feeling than being on your own two feet and controlling what is happening to you.

After lunch we went back to the P.T. Department to work with my arms and hands. A lapboard was put across the chair with baby powder spread thinly on it to decrease friction, so that my hands and arms could slide easily. Or some slings were hung up on stands with my arms put through them. The slings enabled me to use my left arm, since I could by now move the elbow and wrist joints. I had to pick little objects up and put them in a can or stack children's blocks. They taped a sponge around an ordinary pencil and I could hold on to the sponge and write with shaky, sprawling letters. All this was designed to strengthen different muscles, but things were going much more slowly than I had expected. All of it still seemed like part of a terrible nightmare.

This was the first time I had seen other people, in bunches, that had P.T. problems. There were older ladies in wheelchairs. Many of them were recovering from broken hips and were learning to walk again. One young man had a bad leg and walked with crutches. One man who looked normal, but was helped by his wife, practiced everything. He went up steps, turned keys, turned over a big wheel with a handle, rode on a stationary bicycle and worked out on the mat. There was an 18-year old boy who had his spine severed at the waist. He was very bitter, and arrived every day on a circle bed to strengthen his arms.

But I'm afraid I never did see anyone with all of my problems. Even when I was in the midst of those people with their various problems, I still felt very different and very much detached from them. I suppose this was due to my lack of communication. There were so many things I wanted to say or ask of the persons with whom I did have some communication, but had to put aside because of lack of time or understanding, that I just didn't feel like getting involved with more people. But this didn't curb my curiosity about them and my ears were busy listening to all information that was unintentionally dropped.

The redheaded nurse had taken part of her training at Rancho Los Amigos Hospital in Downey, California, and thus she considered herself to be very good in the area of rehabilitation. It was her opinion that I should have treatments in the Hubbard tank. She and my physical therapist disagreed, because a Hubbard tank is filled with very warm water and the therapist felt the hot water would be so tiring that I wouldn't be much good for other activities. But Rhea was so insistent that the therapist was willing to give it a try.

Everything was arranged for me to have a treatment in a Hubbard tank. My bathing suit was brought from home. A time was agreed upon with the P.T. Department, and since Rhea felt that she must go in the water with me, she arranged to trade shifts with the day nurse. The day arrived and Rhea got me into my suit.

While doing so, she made me very angry about some completely unrelated subject on which she was expounding. I was angry because I wanted to give my opinion on the subject, and couldn't without her cooperation and assistance, which she turned off on any occasion that she

didn't want to hear what I had to say.

I was so angry about not being able to communicate without help that my emotions got completely out of control and I started crying and couldn't stop. When we got to the PT. Department I was still very upset. Then I cried more because the therapist thought I was afraid to go in the water, even though they had showed me all of the safety devices they used for getting a person in and out and holding the head out of the water.

I was put in and my body just about floated up to the level where my head was held. Everyone was telling me they didn't know why I was so worried about the water, when I nearly floated off the rack I was lying on. The hot water is soothing along with the whirlpool type of action. I felt defeated anyway, so I became quiet and the nurse climbed into the tank with me to exercise my arms and legs, even though she could have reached me from the outside of the tank. She thought that I felt more secure to have her in the tank.

Later we got out and back to the room. Then she told me she knew I was not upset about the water, but she felt it wouldn't have been prudent to tell the therapist so. She gave her reasons which I didn't agree with, and don't remember now. I had that treatment only once.

The therapist knew what she was talking about. I was so relaxed and exhausted after this experience that I couldn't even try to lift a finger. I don't think the emotions had too much to do with this effect, since I had many such emotional bouts and still managed the program for the day. It could have been the combination of the two things, but the nurse told me not to tell the therapist.

GOING HOME WEEKENDS

One of the first requests I was able to get across after I came out of the coma was that I wanted to see my children through a window. I thought then that I would be well in a month or so and I didn't want them to see me until I was normal again. I didn't try to put this fact across, because I didn't think it was possible to see them in the hospital anyway. Scripps Hospital didn't allow children to visit.

However my cute little redheaded afternoon nurse wanted to do something nice for me, so she arranged to have my sister bring them up in the employees' elevator and then whisked them into a small conference room where I could see them and they could see me. I almost felt wrong for having made what I thought to be a simple request that turned into a big production involving many people. Once the wheels were set in motion it was impossible to make my wishes known. My idea was to see them through a window at a time when I would be up in the big blue chair anyway, with nothing to do but sit and think. I certainly didn't want or expect things to get as complicated as they did.

All this went on at a time when it was very, very hard to control my emotions. I was emotional about seeing my children and mad that it took so much effort to make a request and then be misunderstood. So it was twice as hard for me to keep myself under control. But I suppose it did serve to hasten my recovery, because I was determined that my children wouldn't

see me cry.

After they left I exploded, but for that half hour I had to force myself not to show any emotion. Believe it or not, that took superhuman effort. As it turned out, Rhea was correct in arranging all this. It served to get mother and children somewhat adjusted at an early stage, but at the time I couldn't see it that way. These meetings went on once a week until I was allowed to go home for the weekend.

Later, I couldn't see why I should stay in that hospital bed and do nothing all weekend, especially when I had started to eat baby food and the P.T. Department was not open on weekends.

So I spelled out:

I don't want to stay here weekends

I told you I wanted to go home since the airplane ride

My first visit home was arranged for a couple of hours stay. I traveled in a panel truck turned into an ambulance, loaned to us by General Atomic, and again I saw little holes in the ceiling of what I was riding in. That was the first of many scary rides.

I was carried into our house on a stretcher from the ambulance and transferred to a couch that makes into a bed. I had to clench my teeth and close my eyes. Sometimes I couldn't keep from screaming, because I constantly felt as if I were falling and knew I was powerless to do anything if I did. Going up the sidewalk was very scary but the porch steps were a real thrill. I found out that I really should have felt secure compared to some later transfers, like being lifted into the front seat of the car by Vic with a nurse and a strange person helping, or later on when I was carried by Vic and three of my own small children. Well, anyway, I got a lot of practice clenching my teeth and closing my eyes tight. If I was to be dropped I didn't care to watch, since I couldn't do anything to help.

After the first visit home Vic borrowed just the stretcher from the ambulance and I rode in our repaired station wagon and I looked at the holes in the headliner where Larry and I hit the ceiling when the car turned over. I thought if I can take that, I can stand a silly ride in the back of the wagon, where the children sleep all the time. But still it was a harrowing ride. You don't realize how much your body automatically compensates for the turns, stops and starts until you don't have the use of those muscles. I had ridden in the back of the station wagon lying down before when I was well and didn't like it at all, but this time I had to like it or stay in the hospital all weekend. This was the first time in months that I had been able to see the outdoors through the window of a moving vehicle. That helped to distract me from the swaying motion of the car. Still it reminded me of the feeling when I was driving and the car overturned. I could only move my head a little in the station wagon - partly from fear, and partly from the friction of the pillow jammed against my head even tighter than usual. I could see only the tops of trees, buildings or things far enough away. My eyes took a long time to focus from one distance to another, so that, by the time they focused on the far away thing I was watching, we would be too close for me to see it anyway. So I saw a fuzzy world, but at least I saw it. I couldn't tell exactly where we

were, because a new freeway had been opened while I was in the hospital. Also I was not used to looking from that particular angle.

I don't know how many times I had the sensation of falling off a guernsey (a narrow bed on large rollers) as I was rolled down the hall in the hospital for various reasons. I remember very clearly a trip to the X-ray room and being lifted onto the hard black table and the trip back to my room. All that I saw was the different kinds of acoustical tile on the ceilings. I got a thrill twice each week as I rode the dreaded guernsey to and from the car. But the real thrill came when I was left alone in the hall for a few minutes while Vic went to move the car into place and the nurse went in search of some willing strong backs. I was lying on the company stretcher placed on the guernsey. Even though I was sure it was stable I felt much more secure when I was finally in the back of the station wagon. Quite often my children were in the car with me. I hadn't seen them all week so I was somewhat distracted until the next dreaded move.

After a while, Vic decided I could use the big blue chair at home instead of using the stretcher. He had the car's front seat fixed up with shoulder straps and a headrest. The only problem then was to transfer me from the chair to the front seat of the car. This we first tried at home over the garage floor. I am too tall to be put straight into a car from a sitting position, so I had to be tipped. This was accomplished by putting a heavy lifting sheet in the seat of the chair before placing me in the chair, so I could be lifted with the sheet and tipped and placed on the front seat of the car by three adults. Vic held up my back with one arm and used the other hand on the lifting sheet. Another person lifted the sheet on the other side of the chair and the third person managed my feet. Vic then backed into the car, pulling me in after him. By this time I was no longer wearing a neck brace, but the doctors wanted me to wear a Queen Anne brace for car trips, just as a safety factor. Still, I could do something to help. All my energy went into holding up my head, which felt like lead.

It was not an easy thing for two six-foot people to learn to go through a car door together, so Vic had to find by experiment just exactly where to place his feet and just where to bend each part of his body in order to fit and be able to lift at the same time. As soon as I was put down on the seat in a very uncomfortable and awkward position, Vic climbed out the other door, and came around the car to straighten me up and hook up the shoulder straps and seat belts. The straps were uncomfortable, but necessary, because I don't have any control of my balance. Just the gentle force of the motion of the car is enough to topple me over.

Putting me into the front seat was not a comfortable thing for me or Vic, or anyone else helping. I could hear and feel the bones in my neck cracking. I soon discovered that if I made any noise during the transfer, the people got frightened and that might cause a catastrophe. And when I was in the car seat everyone asked the wrong questions as to what was wrong, and it was all over anyway. If I tried to speak it only confused the issue.

The trip from the chair into the car was necessarily over cement, and I thought, "Oh well, if you are dropped it will solve your problems." But then I remembered that it would create more problems for others, so I was scared again. I knew that it does no good to be scared, but just try and tell that to yourself, especially when you are already frightened beyond control.

In this way I finally left the hospital for the weekend in a sitting position. I at last saw more than the ceiling going down the halls that should have been familiar to me, but seemed strange. I could see the doors that we were to go out, and could watch Vic moving the car up to the curb to load me into it. I felt as if the chair was falling backwards when the nurse left me for a few minutes to find some help to move me into the car, but that seemed much better than the feeling that the stretcher was falling off the guernsey, and I managed to keep quiet while sitting alone in the hail. We had practiced the transfer to the front seat in the garage on a smooth surface, but the first time at the hospital was just enough different to give me a real fright. People had to step down over a curb with me, and I couldn't keep my eyes off that formidable step. It didn't occur to me at the time that I had gone over this same curb many times on the stretcher.

It was very nice to be sitting in the car again going someplace familiar. At least I could see where we were going. But I didn't realize that you can get very sore sitting on what used to be a comfortable seat if you don't move any muscles. I don't think most people realize how much they move when they think they're sitting very still. After about fifteen minutes I began getting sore and after about thirty minutes it became intolerable. Even though we were in the middle of the street with all kinds of things that I hadn't seen for months, and had never expected to see again, I couldn't keep quiet. I tried to indicate my distress without exciting Vic, who was driving. I finally managed to get my message across. When he could, he pulled over to the side of the road. He and the nurse, who was riding in back of me, tried to move me a little until we could get home. I don't think I realized even then that I was sore because of muscles that wouldn't move.

Before I was paralyzed I didn't notice that most car seats lean back. It can be highly uncomfortable to be strapped in leaning backwards, and have the motion of the car force you against the straps when braking. It's impossible to hold my head up straight when accelerating. There is a typical car headrest, but it might as well be gone. A child usually sat next to me as protection, and this put the headrest in the wrong place for where I was placed.

Then came the reverse process, that of getting me out of the car and into the house. We now have a ramp going from the patio into the living room, but at that time the only way to move me into the house on a level entry was through the kitchen. The garage is on a lower level than the house by two steps. Even though the garage is next to the kitchen it is still necessary to go out the front of the garage and all the way around the outside of the house to a level entry. That was a thrilling ride, too. Often I was placed improperly in the chair, but it was faster just to get me in the house and on the bed than to try and straighten me out in the chair. Sometimes I was slouched way down and felt crooked in the chair. This ordinarily shouldn't bother too much, but I felt like I was slipping slowly out of the chair. Around corners it seemed the whole chair was going to tip over with me in it. You would think that by this time I would be used to this sort of sensation, but it still scared me. Sometimes it was necessary to go very fast, because I needed the bedpan.

The second time I came home I stayed all afternoon, and the third time I stayed all night and the night nurse got a day off. She kept telling me that she was insulted that I preferred that "funny looking nurse" (Vic) to her. It had been four months since I had been with my family

overnight. Thereafter, I was allowed to go home for the whole weekend every week.

At home the hours went fast, because there was always something going on. Quite a contrast to the long hours spent in the hospital room. The three oldest children were pretty good about my illness, showing a natural curiosity about the external plumbing, the trake, etc. But the little one, Karen, was only three years old and she was scared of all this strange stuff and wouldn't come near me at first.

Sunday morning Vic and all the children, except one of the boys, went to church. While they were gone time crept very slowly. There was no one around who could put me on the bedpan if I should need it. I would try my darnedest to last the hour and part of the next hour. Sometimes I would make it and then sometimes I wouldn't.

I always had the feeling that once I got home I would be able to get out of bed. Once again I experienced the disappointing shock of not being able to move when I told myself to get out of bed and get to work. There were many things that needed to be done. Before the accident we had added a new section of living room, converting part of the former living room to a dining room. I had just finished moving the furniture into the new part of the living room and the dining room furniture into the old half of the living room. There were still many things to do, and many things that were done as a temporary measure until either Vic or I could manage to find the time to do them properly. But out of necessity the new dining room had been turned into an additional bedroom. A sliding door had been ordered, painted, and installed while I was in the hospital, so that both the new and the old parts of the house looked very strange.

The children were running wildly in and out of every door (of which there are five), not paying any attention to their feet which might be bare, muddy, covered only with socks or have slippers or shoes on. And all the time Vic was telling me how they all had escaped being sick that winter. I began to doubt my own judgment, because there had never before been a winter without someone being ill. Many of the instructions that were given to the children made me wince. I just had to swallow and tell myself that they had survived healthily so far, so I must be wrong. Also, I realized that they were forced to take much more responsibility than most small children. Since I was the cause of all this, I didn't feel like being a disciplinarian.

Then things got to the stage where I just couldn't stand it and I had to talk, forgetting that I was hard to understand. By the time I said what I had to say, it wouldn't be appropriate any longer, or I didn't get it all out. Sometimes I had no control over the sound, and everyone would take my noises as crying when I was really trying to make letters. That was the last straw, and I would end up crying. It was almost akin to when Rhea told me to get mad and do something. But when I was mad I was very noisy and she would tell me to control myself.

When I went down to the P.T. Department to stand they put what they called a safety belt on me. It had loops on it that the people who were holding me up could grab on to as support for me. The P.T. Department also gave me exercises to do on weekends. My nurse decided that I should get the full treatment, even on weekends, so she looked around the house and fashioned a home type safety belt. When she came home with me I stood even on weekends. It was something to behold. Vic pulled me up and stood in front of me. When I was up, the nurse

stood in back of me and pushed on my hips while my two sons, who were then 7 and 9 years old, each locked one knee in place and held on for all they were worth.

Then some time went by, and on weekends we started having a nurse only during the shifts going to and from the hospital. One weekend my oldest sister came to visit so Vic decided that with my sister's help I could have a standing session. I agreed to the plan. Just as I was being pulled to my feet I felt a bowel-movement urgency and began to yell for them to wait. This, of course, was taken by everyone as a sign that I was frightened by what was happening to me, so I was ignored and the plan proceeded. Just as I went up straight, I also went plop, like a horse. I was wearing pajama bottoms and a hospital gown, so things didn't become apparent for a while. I stopped yelling: it was too late then. Silence was taken as a sign that I now felt safe. But the boys were below holding on to my knees, and the plop began to drop and landed on the rug and on my oldest son's pant leg. He said, "Ugh," but held on. Finally, Vic got the picture and that standing session was cut short.

On my first few visits home from Scripps I wanted my youngest daughter, Karen, to come near me. She was still a bit frightened by all the strange gadgets attached to me, and I didn't want to scare her when she finally got up the courage to come near and sit with me. So I endured great pain just to have the little wiggle worm under my right arm. Her older sister, Linda, always beat her to the less painful left side. Little does Karen know that she helped me to get through a part of the very necessary painful stretching. She was only three years old at the time.

SPEECH THERAPY

I started speech therapy during the time that Angie was with me. I had to learn things that you would imagine to be instinctive, such as to inhale before trying to talk. I had certain exercises to do that must be repeated thousands of times, with the tongue, lips, jaw, and had to try to coordinate all this with breathing using the nostrils, diaphragm and ribs, and try to get some sound out using the vocal chords. The first time I managed to make a squawk there was great jubilation by my nurse and the girls at the desk.

I first had speech therapy sitting up in the hospital bed. Much of the practicing was done with the bed flattened out in a horizontal position. I found that it was much easier to make a sound when lying down. At first I couldn't understand why it was so much different in a flat position. Then during a conversation between the speech therapist and a nurse, the reason became clear. When I was sitting up, my diaphragm had to fight gravity. I had heard about the force of gravity for many years, but it wasn't until then that I realized it to be a really strong force and that it affects so many things that we do in our daily life. For instance, I understand why it was easier to learn to pull down than to lift up. Before, I knew there was gravity, but took it very much for granted. Certainly it would never cause me any trouble.

In speech therapy, I learned, the hard way, that you have to inhale and get air into the diaphragm and then push the air out, against gravity, in order to produce any sound. This, and many other things you learn in early childhood and as an adult you don't remember having gone through this experience previously. Therefore, you have nothing with which to compare the

difficulty. But I know that if the first experience is even half as difficult as the second, children really have something to be proud about when they first master some new accomplishment.

Later I usually was in the wheelchair for speech therapy, because it held me in a straight position. But my urinary habits didn't allow me to stay in the chair very long. Really, there seemed to be a definite correlation between sitting me up straight and the need to urinate. I had learned to urinate in a horizontal position while in traction before the awful surgery, but it happened automatically for months after the catheter was removed whenever I was in a vertical position.

It was embarrassing to get all encased in the chair, lapboard and slings and then discover that I needed to urinate. Could I wait until the activity was finished, I was unstacked, and back in bed, before asking for the bedpan without putting the nurse into panic? I found I might as well try to hold on, since the nurse couldn't possibly get me on the pan in time anyway, and I thought she would think that I deliberately waited for this opportunity.

Yet, it takes all my concentration to tighten those muscles even a little bit, and it takes the same amount of concentration to pay attention to the lesson. So I tightened up my muscles, producing a big shudder in my whole body, and hoped the muscles would stay tightened up while I concentrated on the lesson. In the meantime, the nurse and the speech therapist were concerned about what caused the shudder, and were telling me to relax, feel limp. So I tried to follow their instructions and still hang on to the urine. All of a sudden I felt things about to happen. At that point events were beyond my control and they happened. A few seconds later a little puddle appeared on the floor. It wasn't discovered for a few minutes, since they were still discussing the shudder. When it was discovered they matter of factly, but with humor, wiped things up and went on with the lesson. When the lesson was over I discovered that I was mighty sore from sitting. I needed to be moved, but I didn't want anyone to see the mess underneath me. Fortunately, I didn't have to ask to be moved, because the nurse set about the business of cleaning me up. Still it seemed like an eternity until I was moved off my sore bottom. Finally I remembered that I'd been sitting in the P.T. Department's best wheelchair. They told me it absolutely must not get wet.

The EQUIPMENT HASSLE

The P.T. therapist wanted to change me to a regular wheelchair but I wouldn't have any part of that. I had tried one before and found the backs of the chair to be much too low. It felt as though my spine was breaking into two pieces when I was in a chair with a low back. So I was panicked of the day when I would have to change to one.

Vic, or one of the children, had stood in back of me to hold my shoulders when I was in a low-back chair. I knew that the nurses couldn't do this all the time, especially Rhea, who seemed to feel that to be frightened to death and come through the experience was the only way for me to learn: like throwing someone in the water to sink or swim. Vic had deliberately, and of necessity, stepped away from the low back for a few minutes, and I had forced myself to be quiet for as long as possible before going into an uncontrolled cry.

Somehow I made it known to the therapist that I didn't like the low back on wheelchairs. In a day or so she showed me a chair with an extension on the back. I wasn't aware that such a thing existed. I was then perfectly willing to exchange chairs. I was unaware of the fact that being able to change the position of the blue chair allowed me to stay in a sitting position for a longer time than in a chair that was fixed in one position. I should have realized it, because I wouldn't be as sore after the blue chair was lowered a little or put back up into an upright position. But I was very eager to progress and changing to a regular chair seemed like a step in the right direction.

Angie was fearless and would try anything. One time she decided to get me out of bed with a Hoyer lift. She knew that the one-piece sling was narrow and that it hurt my back, because I had been weighed using it. Also, I was afraid that I was falling off, so she used a two-piece sling with chains. On the way out of the bed things went pretty well, with me gritting my teeth to be quiet. I felt I was slipping through the middle, even though my physicist husband had assured me that it was impossible. But on the way back to the bed the nurse forgot to spread the feet of the lift. When I was over the bed the lift tipped over and I landed with a crash on the bed. Needless to say, she never tried the lift with me again. A couple of other nurses tried it later and couldn't understand why I was so panicky.

One day Angie showed me a pamphlet about a circle bed. It had wonderful things to say and showed pictures of all the different positions a person can get into by just moving the position of the bed. Eventually the person is supposed to be able to walk out of the bed from a standing position. It looked simple enough in the pictures and I had great hopes this kind of bed would help me to be normal, able to leave the dreaded hospital, go home and resume being a wife and mother.

The bed went around like a Ferris wheel. You could be turned on your tummy (the way I used to sleep whenever I didn't feel well or had trouble going to sleep). It works by padding the appropriate places, placing a framework covered in canvas over the top of the person in the bed, and tying it down. Then the bed is turned over so that instead of lying on the bed, the bed is on top of the person and the person is lying prone on the canvass-covered frame. The bed has all kinds of gadgets on it, including a pot so that the person can go to the bathroom without having a bedpan. (The hole was in the wrong place for me so I had to use the bedpan anyway.)

I had heard a girl friend describe a circle bed before, but I thought they were flat and round like the beds you sometimes see in expensive houses in the movies. In fact, in one of my dreams while I was in a coma I thought that Vic had purchased one for the hospital in Oregon. When you were turned over in my dream bed they just rolled you around, pivoting around your head in the middle of the round bed.

There are various stops on the frame of the circle bed which are supposed to ensure that the bed stops at a certain position, even if the person operating the bed forgets to stop. I couldn't see well enough to find out how the bed operated when it went all the way around. Not having any control of my muscles to hold on with in case the bed went too far, I was very apprehensive while the bed was in motion. I was told many times that it was impossible to fall, but I couldn't see it myself so I didn't trust it. An ordinary person could jump or hang on but I was completely

at the mercy of the bed. In my state it seemed like an unstable monster. The bed also seemed much narrower than an ordinary hospital bed. I was assured that there were even smaller circle beds. A lot of comfort that was.

So Angie installed the circle bed in my room. While the bed was being put into the room I was in the big blue chair, which was rolled out into the hall. I think it was then that I realized that I couldn't hold myself up straight, even in a sitting position. My sister was there at the time, but in my room with the nurse, who was busy directing operations for the installation of the bed.

Besides realizing that I couldn't sit up, I felt as if the chair was falling over backwards and to the side, and realized that I could do nothing about it. I felt very much alone and helpless and tried to concentrate on the passersby in the hall. I sat there for what was to me a long time, telling myself that this was just plain ridiculous. I guess I didn't convince myself, because I went into one of my uncontrolled screams.

I soon found my sister holding on to me. I was then put into the bed when it was ready. Since the nurses decided to take it easy with the new bed and let me get the feel of it, I was only rocked back and forth a little that day, and for several days. So I still needed to be turned on my side manually. Once, during the turning process when my legs flopped out of the bed, a helper nurse started yelling, "She's falling, she's falling!" instead of just pushing my legs back on the bed. So Angie had to run around the bed and do the job for her. It was very disconcerting to Angie to have happen precisely what she was trying to convince me could never happen. After that, I really was scared when I was turned.

One time when I was in the big blue chair Angie stopped me by a room on the fifth floor using a circle bed, and we watched the other patient go over like a child rolling in a barrel. She seemed to take it all in her stride, since she had done it many times. That still didn't help me figure out why the bed went completely around sometimes and sometimes stopped, and why the nurses called it foolproof. I had visions of the bed forgetting to stop when the canvas frame was not on properly, and I would be put into a standing position and down I would go.

Angie wanted to be there the first time I was turned completely over using the circle bed, but something unusual happened the day it was planned to happen and she didn't get it done. When she left, she suggested to Rhea that they wait until the following day to turn me using the bed. But Rhea was young and eager and confident and she decided I should go over. But we didn't have a faceplate. So the redhead decided that we could borrow the faceplate from the circle bed on the fifth floor. It didn't fit me at all. Since it was a borrowed item, she didn't want to change it, but still proceeded with her plan. She got me all trussed up in this rig and Vic walked in. So she proceeded with the up-and-over show. Meanwhile, I was scared to death, but was containing myself. I was put in a standing position and felt as if I were being crushed but kept telling myself, "This will be over soon and next time will be better." Then she put me over on my tummy. I was still afraid, but getting used to it.

But the pressure of my heavy head on the faceplate became too much for me. Not being able to say what the problem was, I began to scream and the nurse decided I was really frightened. Her philosophy was, if she is scared, just leave her up there and show her there is

nothing to be frightened about.

So there I was, screaming and helpless and in great pain and no one knowing the real problem. The next day I was asked if I liked the old bed better than the new one and I truthfully answered, "Yes." No one asked me until after the circle bed was gone what the problem was, or if I was willing to try it again. They probably didn't want to try it again. The whole time I was in that bed, I was extra tense, so maybe it was just as well. Anyway, all I heard was how much trouble I had caused for the Housekeeping Department.

HOSPITAL CARE and FEEDING

Soon Angie quit to be married to the Navy doctor. I thought at first that the third day-nurse, Jean, was going to be a colossal flop. She looked for all the world like a typical old-time aloof nurse, who took care of others but not herself.

Jean quickly realized that I didn't like any hair-stroking "poor dear" treatment. After a while, I discovered she had a terrific sense of humor and was a very good nurse, as had been reported to me. I learned she had started her nursing career at the age of seven when her father had a stroke and she had to pivot him in and out of bed on his good leg. I believe she lost both parents at an early age. She was brought up by her grandmother, with whom she got much practice in massaging sore muscles.

From this I suppose she developed her knack for relaxing muscles. The first few days she was with me she watched the physical therapist put me through some exercises for about a half hour to 45 minutes. After that she decided that I should be more relaxed for these exercises, so she massaged and exercised me at the same time until I was so relaxed I was practically hypnotized. Of course, I also took the prescribed relaxant, which was partially responsible, but all the nurses gave me the same medication. Jean just seemed to have a magical touch.

One day Jean asked me if I would like to have a shower instead of bed baths all the time. I must have looked surprised because she said, "You don't think it's possible, do you?" I indicated that I didn't see how, but it sounded nice. So she explained to me that in this fairly new hospital there was on each floor a large shower room with a wide door. On this floor they had never used it for a shower before, but were using it for a storage room. She thought she could get permission to put the stuff in the hall while we used the room. She would put me under the shower right in the chair. I was surprised that we could get the chair wet, but she said we would just dry it off really well.

So this is what we did. She put me bare in the chair, wrapped me up with sheets and bath blanket, loaded up my lap with soap, washcloth, towel, etc.; and down the hall we went to the shower. She discovered that some bare skin showed in back where the chair back didn't quite meet the chair seat, so she draped a towel across the back and made me decent. After she got me in the chair, but before we went to the shower, she covered the bed sheets with something waterproof and then something absorbent. When we were through, she plopped me, wet, back in the bed and dried me off there. This was done twice a week.

Soon Rhea decided that I could also have my hair washed in the same fashion. That sounded wonderful to me, but I didn't realize that I used to hold my breath automatically when I put my head under the shower. The only trouble with washing my hair this way was that I was now unable to hold my breath, even when trying very hard. My breathing was, and still is, very shallow. I'm unable to stop it at will. When I was put completely under the shower I inhaled water. Even though the water was pouring down it felt as though I was inhaling upwards. So the whole time I should have been enjoying the shower and shampoo I was worried about inhaling water.

But it was either that way, or the miserable way tried one time by Rhea and her friend, an aide studying to be a nurse. They did it once in the bed with pans and pouring water over my head into a basin. This meant that one person had to hold my shoulders up over the pan, while the other person scrubbed and poured the water. It was miserable for all three of us. But no one else was willing to try to shampoo me in the wheelchair as Angie and Dot had done it, so I was stuck with going along with Rhea or having a dirty head, which I was unable to scratch.

When I was in the shower with Jean I felt secure enough to be daring, and tried to lean forward and stick my tongue out under the water. I normally like the feel of water running all over me. She put her arm out a few inches in front of me to make me feel as though there were something to lean against in case I could move those few inches further.

The showers were usually done just at the end of the day shift. I always hoped Jean was on schedule on shower day, for if not, the shower ran into the afternoon schedule, which gave me plenty more to worry about. In the first place there were no orderlies to be found in the afternoon, or maybe Rea just didn't have the knack of finding one. So I had to be transferred from the chair to the bed while partially wet and slippery by a crew of females, who looked too small to handle big me. Then I could worry about Rhea's basic philosophy, which allowed her to make me feel as though chances were being taken, even though, in retrospect, I'm sure she didn't take any unnecessary risks.

The showers allowed me to do without the 4:00 a.m. bath on shower day. Soon I was having the bed baths on the afternoon shift too, and could sleep through every night except for being turned and put on the bedpan. I found out much later that this change came at Jean's suggestion.

For the first time in my life I hated the thought of mealtime, although the hospital had a very good staff in the kitchen and the head dietician took a personal interest in trying to make nutritious, balanced meals that I could manage. When I was fed through the stomach tube I used to hear the trays clattering in the hall at mealtime and wish one was for me. Now that I was getting a very attractive, thoroughly ground or mashed tray, I was no longer interested in eating, because I coughed with each bite. Mealtimes were just another activity that I had to learn all over again. Along with all the other frustrations they were very uncomfortable, too. I had to be constantly reminded to chew and swallow. I couldn't tell when I was going to cough; although I could be assured that it would come sometime with each bite. So I got into the habit (bad or good, depending on who was looking at it) of turning my head away from the person with the spoon. The person who was feeding me had to remind me constantly to turn my head toward

her.

I must have gotten into this habit from the constant hilarious teasing of Angie. She told me each morning that she had on a clean uniform and she'd like to keep it that way. But she was so funny that at some time during breakfast or lunch I forgot myself for a second and laughed just after a bite was headed my way. There went another clean uniform. Some of the nurses thought I was just plain mean and was spitting out the things I didn't like. One time when Angie was still quite new on the job, I unexpectedly (to both of us) sprayed her with beets. Such a beautiful red and white uniform you have never seen. The nurses found out a little later that beets were one of my real dislikes and therefore decided that I spit on purpose. The fallacy is that I'm not able to spit even beets at will, but if a laugh is triggered when my mouth is full, you had better duck.

Jean was very conscious of food and nutrition, and would go over the menu with me. She made me pick out my own food. If she didn't think it was enough she'd order more. The only trouble was that enough to suit her was enough to choke a horse. At breakfast and lunch I was obliged to eat as much as I could, but at supper Rhea was there. I picked out all the things I wanted to eat, and she made her dinner out of what was left over. I suppose it's a good thing that I was soon to go to another hospital where they were concerned about me getting too heavy to handle, even though I was still fifteen to seventeen pounds lighter than I'd been before the surgery. Rhea deduced from the size of my meals that I was an enormously big eater, so she gave me very big bites. Before I swallowed that bite, along came another bite, until my mouth was so full that if I had an explosion it was a major disaster. I developed the technique of shaking my head when my mouth was too full, but this seemed to annoy Rhea greatly. I almost felt as if I was at fault for being so slow. What a choice, a day nurse who gave me reasonably sized bites with plenty of time to chew and swallow, but who stuffed me, or an afternoon nurse who didn't expect me to eat too much but wanted me to be fast.

Rhea was quite proud of her ability to assemble traction equipment. Toward the end of my stay in Scripps Hospital I was trying to feed myself with my arm supported in a sling that was held up on the wheelchair by means of a narrow post. Rhea claimed that I was too tired to get out of bed on her shift, so she spent one whole day setting up some traction equipment on the bed to hold up a sling for each arm. The only trouble was that the crosspieces that were meant to hold up the slings were in the wrong place to be convenient or comfortable. The other nurses were always banging their heads on the crosspieces and they never used the equipment. In fact it was just about head height for most people who came near the bed. Rhea was short enough that the equipment missed her.

The day that she installed it I lived in fear of having a piece fall on me. She kept telling me that she wouldn't drop anything on me, and she didn't. But I had a very close call and couldn't keep my eyes from following every movement of the pieces as they were assembled above my head. Why I watched so closely I don't know, because I couldn't have moved out of the way had I wanted to.

All this equipment still didn't allow me to feed myself completely. After a few bites my hand wouldn't hold on to the big handled spoon, nor would my hand reach my mouth, no matter

how hard I pushed it. So Rhea took my arm in her hand and forced me to feed myself. This was very painful for me and resulted in a sore neck and arm for her. So she told everyone how hard she worked for her patient.

In the daytime my arm lasted a little longer, but not much. I felt like an idiot for all the trouble it took to set me up in the wheelchair and then have my arm give out part way through the meal. It took more time to set me up in the wheelchair than it did for my arm to give up the ghost. But Jean recognized this and offered to feed me the rest of the meal. Being the independent type, this made me try harder, but after a few more tries, I had to give up and let her take over. This can be very damaging to the pride, but good for therapy if the person needing the therapy doesn't quit altogether. It's tempting to give up, even for an independent person, but at every meal I told myself, "This time I will not give up," and then I would be very glad that the promise hadn't been spoken aloud.

Usually my meals at Scripps Hospital were very attractive. One time they had lemon pie for dessert. It happens to be one of my favorites, plus being something I could eat with a minimum of choking and coughing. When it came it was the sorriest looking excuse for a piece of pie that I'd ever seen, but it was lemon - something that I hadn't seen for a long time. So I ate it anyway. Jean was there at the time. She was usually quite professional and never criticized anything related to her work, but this piece of pie got to her and nearly choked her while she was feeding it to me. So she decided to show me what a lemon pie should look like. Within the next few days she baked and brought in a pie that would have taken first prize at the County Fair.

Jean and the dietician were always on the lookout for different things for me to eat. She brought in many things and introduced me to persimmons.

Vic and the nurses often talked about how I must learn to do everything again as I did from babyhood, but never once mentioned what seemed to me to be a real difference. Babies are born wiggling and only have to learn how to control and develop their muscles, not how to make them move in the first place. But here I was starting even farther back than a newborn baby. It was rather ironic, since I was the one who had said, "I wouldn't want to live my childhood over again for anything." Jean tried to make me feel better by telling me that I had one advantage over babies, "You've learned to do everything once before and it'll be much easier this time." I didn't agree, but it sounded better than anything else I heard.

One of the things that was very horrifying to me was the fact that I had no control over my teeth. Every time my whole body went into a spasm (which is when your muscles do things you don't expect them to: a violent reaction to a shiver you didn't feel, or your legs jumping up from the knees unexpectedly, etc.) my teeth clamped down tight and began to grit. They grated so hard that pieces of the fillings came off. It sounded very loud inside my own head. The harder I tried to stop, the tighter my teeth clamped together and gritted against each other. Since it was impossible for me to do anything but swallow, that's where lots of silver went. Not very tasty and rather scratchy, to say the least, but it was one way, I suppose, to wear down the silver to the proper matching contour.

Dentists usually advise two visits a year, but I only had managed one each summer and

was planning to have a checkup when I returned home from our vacation trip. So, by the time I got to our dentist a span of two years had elapsed. I was certain that by this time, and all the torture that those poor teeth took, they were surely rotted away. But, to my great surprise and delight, although I had very dirty teeth, there was only one cavity and all the teeth were intact. How they lasted I don't know.

Every nurse had her own method of cleaning my mouth. It varied from not doing it at all to getting the water out with a suction gadget that was hanging from the wall of the hospital room. I don't blame the ones who preferred to ignore the issue, because they realized their own limited reaction time. I was very unpredictable and my teeth were likely to clamp down at any time, despite trying very hard to keep my mouth open. Some of the nurses said I was doing it on purpose. It was sometimes difficult to tell which ones were joking. I really had to admire the ones who worked out a system for doing this job.

One day Rhea called in one of her friends. She worked as an aide in the hospital but was also attending State College for a degree in nursing. They were to pull me up from the bed into a sitting position by the arms, so as to stretch the arm muscles. Since one side was harder to pull than the other, they decided to alternate sides each day. This really hurt, but I was willing to try anything and it did serve to get my back free of the bed for a few minutes. I guess these young girls found it to be harder than they expected, because after one or two times they stopped this particular exercise without an explanation. The next few days I was expecting the exercise and had myself all steeled for the experience, but it never happened, and was forgotten on purpose, I think. I guess they discovered some muscles of their own that had been dormant. Or they found out that they didn't feel so young after one or two times. I think I was rather disappointed when days went by without this torture, after convincing myself that it was a necessary part of the treatment.

Then these same two girls asked me if I minded if they took their break in my room. I said no, forgetting that most girls smoked on their break. They had a lovely conversation, all about whether or not a girl was expected to go to bed with her date, while I tried to keep a straight face. According to hospital grapevine, which seemed to reach even paralyzed patients, it was my fault (as usual) that these girls were reprimanded for smoking in a hospital room. I don't know how the proper authority discovered their deed, but I do remember the girls jumping and tittering when another hospital employee came into the room.

All the hospital employees knew me and quite a few were very friendly. A shy, black man who worked in the Housekeeping Department was one of the people who waved at me whenever he saw me going down the hall in the big blue chair. One day Angie commented that she had seen him in the gift shop, which was very unusual for him. Later on the same day he knocked on my door. He was too shy to come in, but asked the nurse to give me something. He had bought, especially for me, a beautiful get-well card. After that he seemed to put something special into his shy little waves.

HOW MUCH RECOVERY?

We always used the employee elevator when going to P.T. I watched all the happy faces

and wondered what lay ahead for them. I wondered if I would ever leave this place, where everyone was always laughing, joking, and making every act that was so difficult for me look so simple. I watched them and thought, "That was once easy for me, too, so why can't I do it now?" But I had to learn even such a simple thing as how to push a button.

One of the girls who worked at the desk on the fifth floor was a frequent visitor to my room. She was newly married. Her husband also worked at the hospital on the instant positive pressure machine team. At first he came into my room quite often to give me treatments with the machine. She claimed to have had surgery on her right shoulder as a child which damaged some nerves and paralyzed her arm. She commented on how hard it had been to learn to lift her arm and said that she knew something of what I was going through. Other people told me all kinds of tales of miraculous total recoveries. A nurse on another case claimed to have a brother who had polio and hadn't recovered for three years but now did everything, including driving a tractor. The girl who had recovered from the paralyzed arm was always willing to help lift me, but was always given the feet. But at that time I had not heard of anyone else with brain damage. Later I recall that a doctor told Vic about an eight-year old girl who had suffered similar brain damage by almost drowning and had recovered completely in about a year.

Jean had undergone surgery on her shoulders, and, according to Rhea, had only taken my case because she expected me to leave soon. But she never showed any discomfort, even though she must have had some. She seemed quite strong and healthy to outward appearances. She lifted my shoulders with her arms many times, saying only that the lifting was good for her own shoulders. She always took the second hardest position when it came to moving me. The hardest position was always taken by a man. She never said anything, but I could tell she was very intolerant of complaining nurses. One time she asked another nurse to take her position because she didn't feel up to par, and the other nurse procrastinated. So, saying nothing, Jean quickly took the position herself. That was the last time she asked anyone to take her place. I still haven't figured out whether she was trying to save her own feelings or mine.

One time a man was complaining bitterly of a sore toe which was all bandaged up, as if he had just had surgery on it. So they wheeled him into Room 521 to say hello to me and we both had to laugh. Of course, this was after I had been there for some time and was laughing instead of crying most of the time.

One of the night nurses was from the South and had a delightful accent. She had been paralyzed as a very small child, had contracted polio as an adult, but now was nursing again. She had one grown son. She was a good nurse and was delightfully funny. She was typically the southern gal who at first glance you thought didn't have a brain in her head. But you soon found she had brains and good sense. She was the first nurse who seemed to understand that it took very great effort for me to get any sound at all. Her paralysis had occurred when she was very young and she only remembered hearing about it. The one way you could tell she had been ill was that her mouth pulled more to the left side when she smiled.

The guard at the emergency entrance of the hospital also claimed that he had been paralyzed for two years from brain surgery. He seemed perfectly healthy.

Whenever the bed rails were up, nothing else was going on, and my arms were underneath the sheet, I pretended that my hands were moving. It felt as if I was really forcing them to move very much against their will. Then when my arms happened to be out of the covers I tried to get the same feeling while looking at my hands. Lo and behold, some of the fingers were moving; not as much as I had imagined, but moving some. Mostly the motion was on the left hand, but the thumb on the right hand moved very slightly.

Sometime during the time Angie was there everyone started talking about how wonderful it would be for me if I could get into Rancho Los Amigos, a rehabilitation hospital in Downey, California. Wonderful things were reported to have happened there. It was reputed to be the only hospital of its kind on the West Coast. So all kinds of shenanigans were going on, involving doctors, nurses, my husband, the Welfare Department and other hospital officials trying to get me into this hospital. It went on for so long that I finally gave up all hope of ever going there. I got all kinds of stories from the various different people involved as to why it was taking so long. First, it was that they had to have some kind of proof that some of my muscles were responding to treatment. Then there seemed to be trouble, because I resided in San Diego County. Rancho was run by Los Angeles County, and would accept only a welfare patient from another county. Next, I was behind another San Diego girl who had been waiting for some time. Most patients stayed in this hospital for over a year and it took a long time for beds to become available.

As it turned out, I had to be classed as a welfare patient for the benefit of Los Angeles County, while we had to pay the expenses through San Diego County. This was not too good, because my records showed me to be on welfare, and yet my husband got the bill. When you are a welfare patient you really get the works, because the people working with you think the county is paying the bill anyway. It turned out to be very funny that the only reason I qualified is because I am a disabled mother. My children are adopted and come from a different division of the San Diego Welfare Department. If I had no children, I couldn't have gotten into that hospital.

When I found out for sure that I was going to Rancho Los Amigos as soon as a bed was available, I managed to get this news across to my physical therapist. Immediately, the P.T. Department started me on a program of trying to feed myself and generally doing as much as possible. I imagine that they were trying to prepare me for the change, but at the time I interpreted it as a bid to try and keep me in a place I was very anxious to be rid of. Rhea said that possibly they considered me ready for more activity. I felt that the coincidence was just too great for this to be the answer. Neither one of us convinced the other. The last day I was there the therapist admitted that I was getting to be too much for her anyway. She was about five months along with her first pregnancy.

The nurses began to worry about how I would manage among all strangers when I couldn't talk. So they had a conference on the subject. Rhea's father and stepmother lived in Los Angeles. She was single and had taken part of her training at Rancho a few years previously. So she planned to live in Los Angeles and go each day to the hospital in Downey to be a private duty nurse for me on the ward. She had been my afternoon nurse for five months and considered herself an expert in interpreting for me. Since the other nurses had commitments

in San Diego, and they hadn't been on my case for such a longtime, they considered this plan a good solution to the problem.

I was always reluctant to fire her, partly because I had been mistaken about another nurse, Miss Artese, and wondered if I could be mistaken about Rhea. In addition, her red hair seemed like a symbol of life to me, since it was the first sign of reality that I remember on coming out of my stupor. Here in my memory was this face with the flaming red hair, giving me one of her now very familiar unscheduled lectures. The lecture seemed to be something about fighting for my life, and fighting to keep my eyes open and not lapse back into the coma. In my mind, that lecture was the one thing that did make me fight to keep awake. In fact, I fought so hard that I was afraid to go to sleep for the first few nights for fear I wouldn't be able to wake up again.

The sad part of the whole thing was that Rhea was a sweet, well-meaning person who didn't realize how obnoxious she could be.

So when she presented this solution to me, I told her I would ask Vic. Secretly, I was hoping he would say "No." I didn't want to be the only one on a ward of handicapped people to have a private nurse. I was already different enough, coming from another county and not being able to propel my own chair. I asked Vic without telling him my feelings on the subject. He flatly said, "No," then he laughed and said he considered it to be a wonderful opportunity to be rid of this nurse without having to fire her. Then he complained only a little about some of the problems that he was having with her. For the first time I fully realized that my complaints were justified and not those of an invalid who had nothing to do but gripe.

MY FIRST DAY at RANCHO

Five months after I arrived at Scripps, we got word that there was a bed available for me at Rancho Los Amigos, the hospital in Downey, near Los Angeles, that specializes in rehabilitation. It was decided that I would go home Friday afternoon and on Monday go on to the new hospital. I suggested to Rhea that she start taking down the many cards Mrs. Fussy had put up all over the room. It was a good thing I did. Rhea spent all day Thursday taking down the room decorations. Friday was spent packing the things from the drawers and cupboards as well as washing and setting my hair.

When Vic arrived on Friday to take me home, my hair was still wet and up in rollers. So we left the hospital through the main lobby, which I had never seen before, with a dryer on my head. I was screaming because I looked so terrible. While everyone was trying to tell me not to be so emotional about leaving all my friends at the hospital, I was angry because no one understood what made me upset.

The last night nurse apparently worked all night Thursday straightening out my file. The girls at the main desk claimed that they just didn't have the time to sort out such a large file. I had been there from the beginning of September, 1966, to the beginning of February, 1967.

Monday morning Vic put me into the back of the station wagon, lying on a regular

camping air mattress and a couple of sleeping bags, and drove me up to Downey. The swaying of the back end of a station wagon is sickening. When you add that this was the same car which had rolled over and sent me to the hospital for the operation that paralyzed me, you may understand why I gritted my teeth and lived in fear during the first of many such rides to and from Downey.

I managed to stay quiet, though. I kept telling myself that if I made Vic worry about me, he couldn't put all his attention on his driving and we might really be in trouble. Part of the time my fear was distracted by what I could see out of the windows of the car. On the first time I took this drive from this particular angle, everything looked strange. I could see the tops of trees and the tops of some of the buildings and the sky. I tried to figure out just where we were.

We drove into the parking lot at Rancho and I still managed to stay quiet. Vic went in to find out where the bed was and to get a wheelchair. We had borrowed a wheelchair from Scripps for the weekend and returned it to them on our way to Downey. Vic was gone what seemed to be a long time. The sun beat down brightly and I was very hot, but I was looking forward with great expectancy to this new experience.

When Vic came back he had a wheelchair but no extension on the back. A girl came with him to help get me into the chair and to guide him to the right spot. When he opened the tailgate, he explained the delay. The bed I was supposed to use was taken, but they had found another one. They couldn't find an extension for the wheelchair but he would stay right behind me on the way in.

I had heard great tales about Rancho and its variety of chairs, and was assured that this one was only temporary. So they put me in the chair and we started on our journey. It turned out to be a long one, because we had parked in the main parking lot. Rancho is a very large, rambling place, mostly one-story so that wheelchairs can easily go anywhere.

When we were almost to our destination all the tensions of the ride in the car, the new hospital, the low wheelchair, and the long, hot delay, caught up with me and were released in screams. Vic tried to show me the Occupational Therapy Department where I would be working, but my eyes were closed from screaming and filled with tears. I tried to force them open but everything was swimming in front of me. I seem to remember some people telling me everything would be all right, which only served to make matters worse. By that time I was mad at myself for making such a scene and not being able to see where I was going.

At long last we reached the ward I was assigned to, and was put into bed. I busied myself looking around the six-bed ward. Vic went to check in with the nursing office and acquaint them with my idiosyncrasies. He came back with the news that they didn't use air mattresses but turned their patients every two hours. I thought this was some progress, but soon found out that I couldn't stand two hours in the same position. I was all right while Vic was there that day, because he moved me frequently, and I thought I would quickly get used to it.

Vic was to catch a plane that night at the Los Angeles airport and would be gone all week to Washington, D.C. He was to come in at the same airport Friday evening and drive to the

hospital to find out if I could return home for the weekend. It was unusual for a patient to go home over the first weekend. However, since I had already been home many weekends from Scripps they thought that I would be able to do it, but wouldn't know for a few days.

Vic stayed around until it was time to leave for the airport. He tried to give the nursing staff all the information he could. Either the nurses were too busy to listen, or they were used to listening to the families of other patients who themselves could talk. The staff listened with only one ear, or they figured that they would handle me their own way when he left. Anyway, most of the information was never passed on to the aides, who did most of the work with the handicapped patients.

After Vic left things were fine until about an hour later, when I got sore. I needed to be moved, and couldn't ring the bell. Even when I caught someone's attention I couldn't make myself understood. Everyone proceeded to guess what I needed, but no one guessed correctly. After a few minutes they gave it up as a bad job and left me sore and still in the same position.

The bed I had was next to a window, so I tried to concentrate on what I saw, as Vic had told me to do to forget the pain. But I wasn't very good at that, so it didn't last long. I can turn my head a little, so I turned it away from the other patients and made awful faces. Then, when I couldn't contain myself any longer, I started to cry but forced myself to keep the lid on. One of the other patients heard me and rang. So an aide came and told me to stop crying or I couldn't go home for the weekend.

So there I was, in pain from being cramped and wanting to go home very, very badly, and yet being told I couldn't go home if I cried. Soon the other hour was up and two people came in to turn me. Then I was good for another hour, and the fiasco started all over again. But they were still convinced that my only problem was homesickness. My bed was close to the wall with the clock. I couldn't see it clearly, but I could tell in general where the hands were pointing and which was the long hand, so I became a clock-watcher. And sure enough, I was turned every two hours. Then I would be all right for an hour and try to be quiet for an hour. I found the time seemed to go faster if I watched fifteen minutes at a time.

LADIES of the WARD

In the days that followed, I used up part of the long hours by listening to my roommates and learning something about them. I will call them Myra, Milly, Jill, Pam, and Cora. From listening to the doctor talk to Myra it sounded like he thought she was a hypochondriac. There was nothing visibly wrong with Myra. She was in the hospital for tests and left a few days after I was admitted. I don't know how long she had been there. The other girls in the room seemed to be fond of her and were sorry to see her go.

Milly was recovering from an attempted suicide. She had found that her husband was stepping out on her. She had three children and considered herself a good wife and mother. She had seen signs of unfaithfulness, but couldn't believe it until she found out definitely. Then she was at her wits' end and took some household poison, which affected the nerves in her hands and feet. She had learned to walk again but still wore braces on both legs and walked with a crutch.

She had been walking again for two months. She left the hospital before I did, having been there seven months. At this point she was practicing walking in support shoes but still wore shoes with braces for general use. Her sister had her two younger children, but her oldest boy was living with her husband. She was terribly worried about him, because his grades in school had slipped and he was witnessing, at a very impressionable age, a side of life that Milly didn't like. When I first entered Rancho, Milly had worked herself up to a three-day weekend and was not there on Mondays. This made that day extra long for me. She liked to talk and as I listened to her the time went faster.

Milly wore half plaster casts like mine at night to prevent foot-drop. I envied her ability to wrap them herself. She was unable to write but used her hands to good advantage. Part of her therapy was making mosaics of all kinds, and she was very meticulous and persistent. She was usually highly emotional and was even more so now, because she was in the process of getting a divorce.

Apparently she had been very weak when she entered the hospital. She couldn't use her hands at the time and used what she called a smoker. I liked to hear her express her feelings about those first few days, when she had to stay in bed all day and was unable to ring the bell. She said her brother-in-law had rigged up a way for her to ring. It was good to hear someone else being irate about a situation that I considered to be similar, but not as drastic as mine had been when I was telling myself, "You are just feeling sorry for yourself."

Jill had a baby some months earlier. It was never quite clear to me, but either having the baby or something else that happened at the same time caused nerve damage. Jill had undergone surgery for a nerve transplant. She had a very long scar on her face. She didn't talk much, and when she did her speech was mushy. You could tell that it had been affected by nerve damage.

Jill spent most of her day in a wheelchair, but could walk very shakily with the aid of a walker. Once a day she was supposed to walk down to the dining hall in the walker with the help of an aide. But Jill was a very shy girl, and the aides took advantage of this fact. Quite often they would tell her to go in her wheelchair, because they were just too busy to help her walk. Jill was apparently also a stubborn person when she wanted to be. She was taken off physical therapy once because she refused to play ball. Playing ball was used as an exercise in coordination, but to Jill it seemed degrading.

Jill had a very devoted husband. He came every evening and when visiting hours were nearly over, he pulled the curtains around her bed and put her to bed himself. Visiting hours were over at eight and bedtime was at ten, but Jill was usually sawing wood well before then. She left the hospital long before I did, but she was still in her wheelchair and took a walker with her. Her mother lived with her and helped to take care of Jill and her baby.

Pam was an unusual girl. She had suffered brain damage four times. One of those times she had been completely paralyzed. Each time she learned to walk again. She was in a wheelchair now and couldn't walk. How did she happen to have brain damage so many times? Her story was that she and her former husband would go to cocktail parties, become intoxicated, go home and get into a fight, whereupon he would strike her on the head with the nearest object.

She had a boy whom she had not seen for six years. He was living with his paternal grandmother. She planned to try to have the child come live with her and her mother and father when she got out of the hospital. I guessed her to be in her late twenties. She called her former husband all kinds of names, but even from her wheelchair she was still interested in men.

Pam was not paralyzed now, but her movements were much slower than anyone else's except when leaning back in a wheelchair. Then she just let go and flopped back. She was very round shouldered. She had lost her voice and had learned to talk again. I could understand her clearly though most people had trouble.

Anyone who could was supposed to make her own bed each morning. Pam had a jolly good fight with her bed every day. She had spent some time in a rehabilitation hospital in the East. At some time in her experiences in the wheelchair, she had taken a jet flight from the East with her mother and father and then entered Rancho. There were many questions I wished to ask her, but I never got the chance. I did find out that at one period in her life she had been paralyzed for two years. She didn't like to talk about it but did say that the experience was terrible. She hated being propped up with pillows and she had been much worse than I was. At that time I was able to move my head and my left forearm. Pam was uneducated because she had left high school to get married. Ordinarily she was a very happy person, but had a couple of touchy spots that were easily triggered, especially by the right people. She took a delight in horror movies and whenever one was on T.V. she insisted on watching it, no matter what else was on.

One week Pam decided it was her lucky week. She received a large Social Security check. I don't remember exactly how large, but in the neighborhood of \$1300.00. The next day she received a beautiful, new, light-blue wheelchair. The girls who worked in the P.T. Department dubbed it her new Cadillac. With her money she started a savings account for her son, bought a used car for her father, took her family out to dinner, and for two Saturdays in a row went on clothes-shopping sprees for herself. We called her the best-dressed patient around. She owned enough new pedal-pusher and Capri outfits to last her for two weeks, wearing a different one each day. The closet by her bed was fairly stuffed with her clothes, and when she went home for the weekend she would leave some at home and bring others.

Pam was such a fastidious person that she insisted on doing the laundry just for herself every day. She had a ritual in the morning, washing herself and putting cologne in the rinse water that was different from anything I had ever seen. Yet she followed the hospital rules and took one bath a week, taking her bath at home on the weekends. This was encouraged for all patients. Any patient who didn't have a bath on the weekend was accompanied by an aide to the shower or bath, or was given a bath by two people: a nurse and an aide.

Pam and I left the hospital the same day. She had been there over a year. She had just gone through a brain test that kept her in bed for three days. It determined that all her spare cells were not used up and this showed that she had a chance to learn to walk again.

Cora was a hemiplegic: one whole side of her was paralyzed. She had one good arm and one bad arm, one good leg and one bad leg. I didn't discover what caused her problem, because

she left the hospital very shortly after I arrived. She had learned to walk by the aid of a three-pointed metal cane with a full handle. She had a lot of trouble managing her clothes. Some aide or other was always telling her to pull her slacks up. Cora was of young-grandmother age. She also was very bitter about men in general and her husband in particular, yet in the end she went home to the husband and some fully-grown children. But she had the attitude of someone doing it for security reasons only.

Myra left first and her bed was taken by a young girl called Ida. Something had gone wrong in the birth of her third child and had caused her to be in a coma for a while, left her without a voice, and left her hemiplegic. Her voice returned one week after she came out of the coma. She came to Rancho after her voice returned. Ida's sister, Rita, was taking care of Ida's beautiful, perfectly normal baby girl. Her mother and father were taking care of her other two children. Ida was busy learning to do things with her good left hand. She was a spunky and independent girl. In time she learned to dress herself completely with her good left hand. This included hooking her own bra. Rita was a hairdresser and came once a week to set everyone's hair after they washed it themselves.

Rita set my hair one time for a Good Friday service, but it became complicated so I didn't try it again. I hated all the fuss and coordination it required of other people. My occupational therapist, Nancy, asked the aides or nurses to wash my hair in time for Rita. For some reason they couldn't do it. So Nancy asked them to help her put me on a guernsey and she washed my hair during the time I was supposed to have occupational therapy (O.T.). She said no one would believe that she had done this as an O.T. We became almost hysterical laughing at the situation. It became even funnier because she was unfamiliar with the equipment and had to look for everything. I knew where everything was and how to operate the equipment, but couldn't tell her in the available time, so she found out by a trial- and-error method. Then the aides had to put me in the wheelchair so Rita could set, dry and comb my hair.

I had a regular pillow in my chair at that time, but even with the air cushion that I now have, I become very pained in my seat after half an hour and need to be lifted to get the blood circulating again. It feels as though someone is pinching me and forgets to let go.

The aides had been instructed to lift me, but were either too busy, didn't think it important, didn't want to take the dryer off, or used some such reason as an excuse to get out of some work. Anyway, by the time Rita finished I was past the sore point and was fairly numb. I didn't want to make a noise for fear of scaring Rita and the others. From experience I knew they wouldn't know the problem, there would be mass confusion, and my hair would never be finished. If I was going to be in pain anyway I might as well get something done. So I managed to stay quiet by watching all the activity with five other heads of hair. Rita was a real artist with hair and could make anyone look absolutely gorgeous.

After Ida had been there a couple of months I was very surprised to see her fairly loping along with a brace on one leg and using the same sort of cane that Cora had used. This effort made her extremely tired, but she was doing it with rests in between. Ice packs seemed to be effective on her right side and it was slowly coming back to life. Toward the end of my stay she was going up steps with a P.T. aide along for the walk. She was supposed to go home to her

mother and father's two-story house the same day I left, but a few days before this she had a seizure and bit her lip. So she had to stay a week longer. She came a week after I did so we were both there for four months. I only wished my progress matched hers. She claimed it to be harder to get out of Rancho than it was to get in.

After Cora left, I was offered her bed, on the opposite side of the room, close to the door and the T.V. I was the only one in the ward who had to be in bed to watch T.V. Later Ida was offered Jill's bed. It was across from my original bed. Its advantages were the window and bookshelves along the wall. When Ida moved there she found its disadvantage. Laying there it was impossible to see the T.V. through three sets of overhead bars. The overhead bars held up various pieces of equipment needed by the patients. As the patients left, things like slings were left up unless needed by another patient. On my second bed there was an unusual sling in Pam's line of sight. Every so often she asked an aide to take it down. It was still there when I left.

When I moved to Cora's bed, Leslie moved in. She was subject to blacking out without warning, and was there for observation and testing. Eventually she had a fusion of the fourth, fifth, and sixth cervical vertebrae, the same ones that I had fused in my surgery. She was gone from our room for several days before and after the operation and I was extra tense until I heard she was all right. She had the surgery just before I left, and was still in bed. She got up for a few minutes each day, walking with the assistance of two people.

Leslie was in her second marriage and had a darling little, curly-haired two-year-old girl. Leslie had no ugly big brown brace to wear after the surgery and I felt relieved for her.

Leslie seemed to be one of the most intelligent girls in our room. She figured out the spelling routine with me. She was one of the few people in this large hospital who ever tried to talk to me. Therefore, I was able to get a little information across to her. She was of great help, both physical and mental, to all the people in the room. The hospital was geared to people in wheelchairs, but there were still a few things that were almost impossible for the wheelchair patient. For one thing, the light switches were obviously not put in for the patient's benefit.

All the patients spent some time in the snack bar and Leslie was no exception, especially since she didn't have P.T. or O.T. to attend. Quite often you would find her there with her husband and her little girl. Since I was having trouble swallowing, I avoided the place, but had to pass through it on my way to and from therapy. It made me very thirsty and jealous of all who swallowed easily.

After Ida moved into Jill's bed, a black woman moved into Ida's bed. She was in a coma and was fed through a tube in her nose. She also seemed to be a hemiplegic, since she moved only one leg and one arm in her sleep. We had all heard a low moaning and crying for a few days. Some of the more mobile patients had reported that a black woman who was in a coma had one of the few private rooms. Then they moved her into our room. Some of the girls in the room talked terribly about how awful it was that they would have to listen to her crying all the time. Having gone through this stage I knew she couldn't help it.

I also realized that although she was crying and noncommunicative she could probably

hear what was said. It upset me that they talked so badly about her and I couldn't stop them. The nurses who came in to feed her talked kindly to her, but the aides were as bad as some of the patients. She would have her bowel movements right in the bed and the aides who changed her linen were not very nice. Even though she was in a coma, they dressed her every day and put her in a reclining wheelchair with an extension headrest, and sat her out in the hall for part of the day.

She seemed to stop much of her crying after she was moved into our room. Her family came to visit her in the evenings and looked for some sign of recognition. One time my sister talked to them and told them about my progress in an attempt to make them feel better. She was still in a coma when I left.

Soon Milly left for home. I missed her constant chattering, but her bed was taken by another woman who wasn't handicapped, but in for some testing. She insisted that she would be out of the hospital by Saturday to go to a dance. None of us believed her, because we thought we knew Rancho, but she was gone in a few days.

Soon the girl who took Milly's bed left and was replaced by Darlene. Darlene turned out to be a very unusual person. This didn't show up at first, because she was really in pain when she arrived. She was very quiet. She spent the first few days in bed. She forced herself to eat potato chips so she would be thirsty and drink lots of water. One of her problems was trouble with urination.

Soon that problem cleared up and the true Darlene appeared. She had at some time in her life been paralyzed for three years from polio. She was an artist with a wheelchair. Besides being graceful in it she was very fast. The best that I could figure out was that she had recovered from polio, and then had contracted another disease which seemed to have affected only one leg. Her arms seemed to be all right. When she wanted to get something in the room she would go from bed to bed using her one good leg and holding on to the upright posts on the beds. Yet she looked very natural and graceful doing this. Darlene had formerly been a dancing teacher. I saw a picture of her working out on a trampoline. She was way up in the air in the picture.

Darlene's husband was only home on Sundays, so she said that she didn't mind spending some of the weekends at the hospital. They lived in L.A. County but about two hours away from the hospital. Part of Darlene's house was a dance studio. A few days after she arrived she was put into a mat class in physical therapy, (P.T.). This consisted of four patients on mats doing a routine set of exercises that were specified by a physical therapist, (also P.T.). The class was run by an aide to the P.T.'s. After a few days, the aide was telling the P.T.'s that Darlene was too good for the mat class.

I saw her doing the exercises one time. When they told her to raise her legs, one leg went up like a ballet dancer's and the other leg wouldn't budge, despite her straining.

Darlene could do any of the torso exercises better than the teacher. Yet she was modest about her abilities. The teacher of the mat class had to learn from the P.T. that she had formerly been a dance teacher. I thought the exercises were to strengthen the bad leg, but she was taken

out of the class. I hope she was given something else to do in its place. I saw her in a stand-alone one time and she was having a ball. A stand-alone is one of the many gadgets at Rancho to help the handicapped person help himself. You can practice standing and still move about. The person is supported up to the waist and has wheels that are controlled by other wheels that are controlled by the hands.

Later on I saw Darlene practicing walking with her leg brace. She had a full-length leg brace with a locking and unlocking knee. She had worn a brace on one wrist for 20 years, played the piano anyway.

Now the occupational therapists urged her to play without her brace. She found she could play on the piano in the dining hall quite well without the brace on her wrist, though she tired more easily.

Darlene was a Pollyanna type of person. One of the biggest complaints you would hear from all patients was the quality of the food. Darlene said, "I'm pretending it's something I like, and then it tastes good." A few of the weekends she went home, and then she came back more enthusiastic than ever. Other weeks we heard tales of how she went far from the hospital on the main street alone in her wheelchair, or how she had taken the hospital tram to the hospital church services.

AIDES at WORK

When I first arrived at Rancho I was very enthusiastic, hopeful and ready to get working. I must say they got things going for me faster than for the average patient. But things still seemed to happen very slowly. This may be characteristic of a large institution, but the patient doesn't care why. I'm sure now the wheels were in motion, but I didn't know it then and found it very demoralizing to lie in bed when I thought nothing was happening. Everyone was too busy with his or her own concerns to tell me what I wanted to know, especially as I was unable to ask. So I felt as if I were left to rot in bed. After what seemed to be an eternity, but was really only a couple of days, some very nice girls (who turned out to be the O.T.'s and P.T.'s) came around to my bed to talk to me and do some testing.

One of the tests was to stick me very lightly with the sharp or dull end of an open safety pin and have me tell them what I felt. I thought this a rather silly test, but found out that some people lost their feeling. Fortunately, on me the sensations seemed to be intact, except for one little area on the right hand between the thumb and index finger. They tested all my muscles, grading them from nothing to poor to fair to good.

They also told me that it was my job to watch for reddened areas on my own body. They said they would find a way to make it possible for me to do so. I suppose this was the standard spiel, because nothing was ever done about it, and I heard no more on the subject. They did a little testing each time and then came back again another time because they had a different patient scheduled for each half hour, and they fitted in new patients on a few of the unscheduled half hours. There were about six pages of small print to be filled out on muscle tests. A person has more muscles than you think is possible.

Finally the day came when I was scheduled for therapy. This meant that I needed to be dressed and put into a wheelchair. It was done by two aides. All the aides were quick and rough, some more so than others. So by the end of the first week many of my zippers were broken and the aides were pinning my pants together. Pants of some kind were the prescribed dress because P.T. (or Physical Torture as it was called by some patients) was not very ladylike. Getting dressed involved a lot of being rolled around in the bed. Sometimes my head would be hanging over the side of the bed. This was a very uncomfortable feeling when you are unable to lift your own head. I would get red in the face, both from the blood rushing to my head and from restraining some blood-curdling screams.

Pulling my blouse on turned out to be quite a problem. They got one arm and shoulder in and then tried to lift the other arm up and back and stick it into the sleeve. Invariably it got stuck. Then I had a hard time trying to make them understand that it would go on if they would bring the blouse up along both arms together, instead of putting it all the way up to one shoulder first. This was essentially the way I had taught my children to put on their coats and it amazed me to have to teach it to adults.

The morning shift of aides was responsible for a different room each day. Therefore, I had to go through this process quite a number of times. Sometimes I was lucky and one aide told another. This type of thing was supposed to be brought up in their eternal meetings, but someone would always have a day off and not get the word, not understand, or just plain not listen. Some of them dressed me completely in the bed; others found it more convenient to put the blouse on after I was in the wheelchair.

Getting me into a wheelchair was quite a project. My only experience with a lift had been with the two-piece heavy canvas sling at Scripps. I knew I was afraid of falling through the middle in this variety. Here they had one-piece slings but they were made of a very lightweight material. They were also made for average size people, and I had to be placed carefully in exactly the proper position or be in danger of slipping out in transit. Now I had two worries. I was deathly afraid of the material ripping while it held my weight, and I was constantly worried about slipping while in the air. The aides could tell that I was nervous and made a joke of the whole thing by saying, "We'll pick up the pieces." I slipped once in P.T. but the wheelchair was underneath me.

The aides never supported my head. They claimed I could hold it up myself. My story is somewhat different. My neck feels rigid and my head will go back only a limited amount.

After I made it to the wheelchair, the next problem was to get my seat back far enough. I don't think these aides had ever before been faced with a large person who couldn't scoot back for herself. They had quite a struggle getting me back far enough into the chair, and finally managed it by hand with one person pulling under each arm. This really hurt, but I had learned by this time that it created more trouble than it was worth to make a noise. The aides couldn't understand that just pulling under the arms hurts and thought that everything else under the sun was the matter. This only created delay, and the trouble would still be a mystery to them, but the pain was over in a few seconds.

One time during the first week I was there they dressed me all in lavender. I remembered having a lavender blouse, but where did the lavender slacks come from? Vic had packed my clothes to take with me. Everyone complimented me on the lovely outfit. At this time I was still having a lot of double vision. When the pants very, very slowly came into focus I discovered that I was wearing my pajama bottoms. I had wondered why the aides didn't have any trouble with a zipper that morning!

Once during the first week I was there, two black aides dressed me. All the other girls had paid me the courtesy of letting me choose what to wear. These girls put on the one dress that I had with me. They put it on by forcing my arms up above my head and they got it on backwards with the zipper up the front and two lumps in the back. I somehow managed to inform them it was backwards and they took it off, ripping a seam in the process. All these things were repaired on my weekend at home, only to be ripped again the next week.

After a long series of conversations with Vic, my head nurse finally agreed that I could have an air mattress. She insisted that I must be turned, though. This was rather funny to me. My complaint was that I got sore before two hours were up and needed to be turned more often. The air mattress was an attempt to keep me comfortable until time to be turned again. When it came it was a hand pumped air mattress, rather than a circulating air mattress like I had used at Scripps. She insisted that the first time anyone put a pin in it, it would have to go.

Yet I saw her personally repairing it and pumping it up again with a hand pump that looked like a bicycle pump. It seemed to be pumped up in sections, so that sometimes one section would be deflated by having someone stick it with a pin and other sections would stay inflated, making the bed rather wavy. I was rather surprised that I did get the air mattress. I had heard tales that no air mattresses were allowed in the hospital, even if they were personally owned by the patient, because too many pins were used for various purposes.

After I had been at Rancho several weeks my toenails and fingernails and excess hair on my body began to grow. This can be quite a problem, especially when you only get one bath each week. There was no one at home on weekends who would understand how to take care of such a problem, so the only thing for me to do was to ask my older sister, Muriel, who visited me regularly at Rancho, to do the dirty deed. So the next time, she came armed with the proper equipment. She decided that, as this was to be a continuing job, she might as well leave the equipment with me. The equipment included a razor, which I had forgotten was against the rules for patients at Rancho. One of the aides, rummaging through my bedside stand looking for something else, received quite a shock when she came upon the razor. But she left it after telling me I was breaking the rules, and that things of that nature were supposed to be kept in the nursing office. Later on I heard Leslie tell of several suicides within our ward and the adjoining wards. I wondered if the aide left the razor because it wasn't her concern, or because she figured out that I couldn't use it even if I were so inclined.

On the evening crew, the aides were assigned to each room for a month at a time and then they moved on. I liked most of the aides on the evening crew, and it didn't matter too much to me which person had the room. Having aides for a month at a time gave them a chance to get

used to each person's idiosyncrasies. At least this happened while I was in the room all the time.

I hated to see the morning come, partly because we never knew who would be assigned to our room. Even though I wasn't in the room most of the day, I still had to look forward to being dressed, put into a wheelchair, and pushed off to therapy by the morning aides. As you might have guessed, they were not exactly my favorite crew. They included a couple of very nice people, a couple of know-it-alls, a few average type people, and a couple of mean, indifferent people who had worked at Rancho too long.

One of the girls on the evening crew was the only one at Rancho to take a few minutes and spell out words with me when she couldn't figure out what I wanted. She also had a very nice personality and a good sense of humor on a rather low plane. Consequently, she seemed like one of my few friends among the people who worked at Rancho. Then once she had a bad day and kept it all inside, until she exploded at me. She happened to be feeding me dinner, as she had done many times before. She had given me about three bites much too quickly for my turtle's pace.

Then, without any warning, it happened. She told me that I looked stupid and showed me how I looked to her, and she was not going to stand there and feed me if I insisted on not chewing. Actually I was trying to muffle a cough, since it made me especially embarrassed to spray a friend. Well, eating is quite a chore, far from a pleasure for me, so when she asked me if I wanted my dinner I truthfully said "No." She was not about to feed me when I didn't want it, so she threw it all in the garbage.

Her mimicking my face really hurt my feelings, and when she left I howled. Everyone thought I was angry because of skipping dinner.

Later on another aide, who I thought was her good friend, told me that the first aide had been called on the carpet by the head nurse. The second aide said she didn't know what it was all about, but she wanted to make sure someone knew, even if it was only my husband. The funny part was that this second aide and my husband were instantly at odds every time they met. Soon after that, the first aide went on night duty.

Bath day at Rancho was really something. Bathing went on every day on regular schedule, but my day was usually on a Tuesday right after breakfast. They woke me up at the usual time, around six in the morning, to wash my face and brush my teeth. This was done by the night crew just before they went home. Other patients were to get dressed at this time. They always dressed me after breakfast, so I usually fell asleep again after an unsuccessful attempt on the bedpan.

On bath day the bath crew came along before I was put on the pan after breakfast. The bath crew was learning to use a new kind of lift. It fit right over the beds and lifted patients flat out of bed. They were then pushed down the hall and into the bathroom, where they could be lowered directly onto what they called the "birdbath, (A porcelain table with sides and a drain.)

The lift had friction type tabs on it. Quite often the girls got the dark green nylon mesh

sling under me, put the tabs in the frame incorrectly, and started to crank me up. But the tabs slipped, leaving me right where I was. Then they put the tabs in correctly and up I went with a great feeling of insecurity. Then they pushed the lift away from the bed and down the hall with nothing between me and the cement floor but the mesh sling.

Going down the hall in a hospital gown with no covering was an embarrassing and drafty experience. When I was finally lowered onto the birdbath, I felt safe again but mighty uncomfortable as a dead weight on the hard porcelain. Some of the people padded under my head after they washed, others did not. I tried very hard to urinate as long as I was over a drain, but couldn't make myself as long as people were in the room, and especially not with two people scrubbing me. Once I asked for the bedpan and made everyone leave the room. I was successful, but got the dickens for holding up the bath schedule. Other times I was miserable until the lunch hour.

While I was wet and freezing, someone would remark about how hot they were and open the door. The two people then dressed me on the birdbath, put a regular sling under me and put me in my chair with the regular lift. The whole procedure took about fifteen minutes. Every time I took a bath my teeth chattered, both from being cold and from nervousness. I ended up crying for those reasons, plus I couldn't even try to talk and ask for the pan with my teeth chattering and out of control. The crew said, "Don't be such a baby. We're only giving you a bath."

TESTS and TRAVELS

Many of the tests required that I be in a hospital gown and on a guerny. Whether I was sent on a guerny or in a wheelchair didn't matter to me. They had equal disadvantages. I was usually put on the guerny right after breakfast. This meant that I had already been on my back for the allotted two hours. I was put on my back on the guerny, and sooner or later I'd try to wiggle my pinched seat. This, of course, didn't work and by the time I got back to bed and on my side many hours had passed.

Also, I was deathly afraid of a guerny, because it has no side rails. I suppose it didn't matter, since I usually had the sensation of the whole guerny tipping over. Some guernys had straps. On these I could picture the guerny going over with me on it and the straps sticking and people trying frantically to undo them. The fact that I knew guernys to be safe didn't affect my sensation. I could see many other people on them moving about, but I still couldn't convince myself of what I already knew. I was afraid to turn my head or move my hand, for doing so made the tipping sensation more acute.

Whether I was on a guerny or in a wheelchair, I was usually pushed by a messenger girl. These girls did nothing but push patients to appointments all day long. The ward nursing office arranged to have you delivered to your appointment by this service. Sometimes your chart was sent with you, sometimes not, but as far as my comfort was concerned it didn't matter. Even if my chart was read, people wouldn't realize the cause of my discomfort - having a very sore rear end from being in one position for so long. I was all right on the trip to the appointment. Then came the long wait for my turn, then the appointment, then the long wait for a messenger to

return me to my ward. Then the long trip back, only to be left in the hall near my ward's nursing office. Finally, the long wait for the aides to put me in bed.

All these different people handled me, and only the people on my own ward knew I couldn't move or talk. Everyone greeted me politely, and then became sullen, thinking that I chose not to answer. These people (especially the messenger girls) didn't look at my face, but just started to get on with their job. So it became clear very quickly that trying to talk was useless.

At this point I could make sounds only when lying down and then only with great effort. A normal person could say several sentences in the time it took me to take a conscious breath. Anyway, usually while I was waiting for the return messenger, the pain became unbearable.

Having tried everything I could think of without success, I went into an uncontrolled scream, something which I couldn't do at will. No one knew what to do except return me to my ward. There, people who were supposedly familiar with my problems, told me I had to wait my turn; that I was just acting spoiled and trying to be taken care of out of turn. By the time they got the lift over me I was too sore to worry about the quality of the sling, or whether it moved while it was under me.

My first trip away from the ward was to the X-ray department. I had an 8a.m. appointment. The aides had rushed to have me there on time. I got back to the ward at 1 p.m. I probably would still be there if my two sisters hadn't come to visit me. They got tired of waiting in my ward and set out to find me. When they found me I hadn't yet been in the X-ray room. They quickly set out to discover why, and soon it was magically my turn. The X-ray staff was busy that day and there was much grumbling and complaining. One lady on a guerny even asked for a bedpan. I needed one, too, but didn't want to make it known, couldn't anyway, so held on in misery. When I finally made it into the X-ray room, I felt very stupid not to be able to climb onto the table myself and was relieved to have my sisters there to talk to the man. On the return trip I didn't have to wait for a messenger girl. My sisters pushed me quickly back on the long trek to my room, where I was put in bed, given the bedpan and then lunch and then turned on my side. What a relief! I had never expected to see that bed again.

The second test was some kind of brain wave test. Here also a long line-up of people waited for the test, but it went very quickly and was not at all painful and I was back within two hours. I'm afraid the tipping sensation was with me all the while.

The next was another kind of brain test, where it is necessary for them to put what feels like many little needles into the scalp. Then they ask you to hold your breath. I tried many times to hold my breath, but couldn't, so the girl technician became angry with me and hurt my feelings and I began to cry. She thought I was crying because the needles hurt and told me not to be such a baby. She couldn't understand why I wouldn't answer her. She was standing quite a distance from me and looking at some equipment. Sometimes during a crying spell I involuntarily hold my breath. So she finished the test on this basis. My ward was just around a corner, so she had me pushed around there where I was no longer her problem.

Another time I was sent to the dermatologist, who prescribed essentially the same medicine for the redness on my face that had been prescribed at Scripps Hospital. The medicine was delivered promptly, but seldom used, so I had my sister put some on after she worked on the tremendous blackheads that appeared on my face since being at Rancho. The aides washed my face once a day with a slightly warm wet washcloth, but having oily skin I was used to lots of soap and water. My sister visited me three times a week for about an hour in the evening and during this time she washed my face with soap, steamed it and dug out the blackheads that were loose and then put the medicine on all the irritated parts. It was rather funny later on when one of the aides remarked how my skin had improved since I came to Rancho.

I went twice to have a fluoroscope made of my throat. The first time I went through the regular rigmarole, being put on the guerny, waiting in the hall for a girl to push me there, the long trip through connected, low, rambling buildings and covered walkways and the wait in the hall for my return. The outdoor walkways were meant to be a smooth transition between buildings, but the guerny always hit a big bump at each end. When I reached my destination and had waited for about ten minutes my P.T. showed up and requested that a certain doctor, one who specialized in the muscles of the throat, do the fluoroscopy. He was not in that particular day so she made an appointment for the following Monday and pushed me back to my room.

The aides, who were forever calling the therapists names behind their backs, had a fit when they found out I had not had the fluoroscopy and they had to go through the whole process (including calling the messenger service) all over again. I guess my P.T. got wind of this, so she offered to push me there, rather than meet me there. That's what happened. When I got to the place again the doctor wanted me sitting in a straight-backed wooden chair. So my P.T., the doctor, and his lady assistant picked me up and put me on the chair, and tied me into it. They put me, chair and all, into a big piece of machinery, and then closed it up until there was barely space for the chair. It felt as if the walls were closing in to squash me. Then they gave me some concoction to drink. It tasted like chalk and was about the consistency of a milk shake. Here for the first time since the surgery, I had something to drink in a sitting position. I was afraid I would choke and spatter all over everyone and the expensive equipment. But it was thick enough that I managed to get it down without an explosion. Then the doctor and the P.T. viewed the action of my throat on a television screen. They seemed to be fascinated by what they saw. The doctor reported everything to be working slowly, but not coordinated. He said all he could do was tell the P.T. and me that it would be better in time. But he didn't say how much time. Then they returned me to the guerny and the P.T. pushed me back to the ward and the regular grind went on.

O.T. and P.T.

I had occupational therapy (O.T.) for an hour and a half in the morning and physical therapy (P.T.) for an hour. Then I was put back on the bed, given the bedpan and fed lunch. In the afternoon I had P.T. for an hour and a half and O.T. for an hour. Then I was returned to my room to sit and wait for the afternoon shift of aides to undress me, put me to bed and give me the bedpan. Dinner was at five for those who could go to the dining hall and about a half hour later for bed patients.

One of the first things they did in O.T. was to decide on the type of hand braces I should have. This seemed to take a number of days, with much conferring between several people. Afterward I spent many hours in the hospital orthotics shop, where all the gadgets were custom-made for the patients. For me the visiting presented problems. The first was that, even after many months of inactivity, just sitting and waiting was frustrating. Fortunately, I like to watch people, so I spent much time watching the various patients and their many problems. Here, as everywhere at Rancho, the variety of human abnormality was staggering. I saw darling children who couldn't walk, but otherwise were typical children. I saw adults with many different types of difficulties, and with many different modes of transportation. I think the most unusual thing I saw was an extremely thin man who was on his stomach on a gadget that looked like the back of a cement truck, only much smaller. He was brought into the orthotics shop to be fitted for some kind of a brace, so I assume he couldn't be moved off his peculiar circle bed.

I had heard glowing reports about how the patients at Rancho were supplied with all kinds of fancy gadgets to help themselves. I even heard how one lady was fixed up with a bell she could ring by turning her head. So I waited for them to provide me a bell that I could ring.

After three weeks, when I was home for the weekend I was slightly unhappy with the place and mentioned to Vic that I was unable to call if I needed help. The next week they were very prompt about fixing me up with an oversized call bell that I could ring by touching any part of my hand or arm on the large lever that activated the bell. Now I had the bell, but most of the time the various aides inadvertently forgot to place it within my reach. Also I was informed by one aide not to ring it to be moved. This was after another aide told me not to hesitate to ring if I was uncomfortable. Then I found that they always asked first if I needed the pan, so I started saying "Yes" always. They had to move me to put the bedpan under me. The trouble then was that I went from cramped muscles to sitting on hard, cold steel. The aides were angry if they put the bedpan under you for nothing. So I couldn't win by saying, "Yes," to the bedpan in order to be moved. But it didn't bother them one bit to put you on and then go for a break, expecting you to ring for another aide to take you off. Only sometimes I couldn't urinate, even though I may have been sure I was about to wet the bed. So then I was still sitting on the hard, cold thing an hour later, wanting to be off, but not wishing to face the remarks that resulted.

Another problem occurred when I had the bell within reach. It was hard to exercise my arm when it might accidentally ring the bell and I would be unable to explain that it was a mistake. Meanwhile the aide thought I needed something and was guessing everything under the sun.

After a mobile arm support was ordered for me by orthotics, the O.T.'s spent much time adjusting it to get it exactly right for my stature. Before my own mobile arm support arrived I had one that was borrowed from O.T. This allowed me to do many things that I was unable to do without support for my elbow. The gadget was in a fixed vertical position but allowed my elbow to move horizontally. Thus I could move my left forearm in many directions.

One of the things it allowed me to do was type with one finger on my left hand. You can't imagine how eager I was to get at that typewriter after many months of only being able to spell with very few people, and yet how frustrating it was because it was so much slower than I

was used to typing. And how long it took for the O.T.'s to set me up for typing. And how frustrating it could be if my O.T. was gone and something needed adjusting in order to type. There was the typewriter, but I had no way to get to it and no way to tell anyone what was wrong.

I was allowed to type for only a half hour almost every day. It took the half hour to get set up to the typewriter and type about six lines if I had made up my mind what I wanted to say. It also could be very frustrating, because there were many things I wanted to say but not write down. One day my therapist could tell I was pretty angry when I got to O.T. So she set me up for the typewriter and told me to take out my frustrations on the typewriter, which I did. I was angry with the ward, because aides gave me pieces of information that seemed to contradict what I had been told earlier. "Be sure and ring if you are at all uncomfortable." "Do not ask to be turned." "Be sure to ring if you want the bedpan." "Do not ring at mealtime," etc.

I just wished they would make up their minds and said so in no uncertain terms on the typewriter. I was so mad that my O.T. changed her plans for me and I typed much more than my allotted half hour. Fortunately there was no one scheduled for the typewriter for the half hour after I had it. I also found out that I could type much faster when I was angry. I was still sore on my bottom and had a burning sensation when I sat for a half hour. This time I had the burning sensation, but knew that if I stopped to be "depressed" I would never get back to the typewriter. So I just ignored the burning and kept on typing.

A few days later my O.T. asked if she could use my typing in a meeting with the nurses and aides, since they very seldom got the patient's viewpoint. She later told me to keep on writing down my feelings as therapy for my frustrations, but she would keep them confidential. The last batch, instead of solving problems, had caused more hard feelings between the therapists and the ward.

To be "depressed" is to be lifted off your sore bottom and have it patted to get the blood circulating again. This can be done in two ways: either by lifting you up from the back and around the waist, or by a side to side tilting. In P.T. I was not 'depressed' very often, since I was moved to a different piece of equipment each half hour. My therapist lifted me whenever she saw me in the hall. Fortunately she was a tall, strong young girl. But in O.T. it was necessary to use the side-to-side method. My occupational therapist had a fusion in the lower part of her back about six months previously and couldn't lift me.

In the side-to-side method the person sits in a chair beside you, takes off the side of your wheelchair, bends you over on her lap and pats your bottom, repeating this process for each side. This method is much slower but it much easier on the person who is helping you.

For me it was a mixed blessing. I was using a chair that had funny little knobs sticking out at about knee level, so that every time I went over in someone's lap the bone in my knee pressed very hard against the knob. So while my bottom was being relieved my knee was in great pain.

The other method has its drawbacks, too. If I was lifted from behind the chair, around the

waist, the person's arms usually slipped up and crushed my breasts. Besides being painful, this could be very embarrassing, especially if a man was doing the lifting.

When I typed, I had to remember what I had already typed, because I couldn't read it. I could make out the keyboard but had no idea what was on the paper. Sometimes I had double vision and then things really got confusing. Fortunately, I was able to close the left eye and see only with my very weak right eye. The only trouble with doing so was that everyone near me became concerned about something being wrong with my face since I was unable to close my eye without drawing up the whole side of my face.

One day the therapist decided to give me a time test. Then I had to confess to her that I couldn't read the print. This was embarrassing to me because I had been used to having extremely good vision. So she found some large print and asked me to copy it, meanwhile ordering an eye test. I was sent twice for eye examinations. It was decided that I didn't need glasses. But I still couldn't read ordinary print. So I went on typing by memory and fuzzily seeing the keyboard. We later found out that they had checked only my distant vision. My eyes no longer focused nearby. So two long, miserable trips were a great waste of time.

Since then my vision has improved ever so slightly. I can now every once in a while make out ordinary print if I really concentrate on it for a longtime. In Rancho I didn't have a chance, even with great concentration.

In order to give me some more mobility the P.T. Department decided to try me out in an electric wheelchair. They had to look long and hard for one, since it had to fit me fairly well and the control had to be left handed. They finally found one that was owned by a patient who was recovering from multiple sclerosis. It turned out to be what is called a junior chair but as I did just barely fit into it, I used it.

I still had problems going to appointments. The messenger girls didn't realize I had to have my mobile arm support and hand brace to operate the chair. If the ward nurse or therapists fixed me up and sent me on my own, quite often my arm slipped out of the mobile arm support and I was left stranded. Going from therapy to the ward there was always someone passing by who was familiar with me, but on a long trip there were only strangers.

If they took me, the messenger girls griped about having to push a heavy electric chair. I wanted very badly to have them use the electric power, but I was unable to tell them how, so I had to sit there and listen to them tell everyone they knew how awful I was to have an electric chair and still expect to be delivered to appointments.

Some of the other things that I was able to manage in O.T. with the aid of other people, the mobile arm support, and hand braces were to do mosaics, brush my teeth with an electric toothbrush, learn to feed myself, try writing (at which I was never very successful) and do some arm exercises on a special table.

My favorite piece of equipment in P.T. was the tilt table, although, as with most of the equipment, I was petrified until I was strapped on. A tilt table is just what it implies. When a

person is laid on it, it is in a horizontal position. Then the person may be cranked up at any angle to a vertical position. I stayed on this for an hour a day, because the therapist knew that I liked it. Why did I enjoy it? It gave me the sensation of standing alone and took the weight off my bottom.

I was also laid on a table and had weights put on my diaphragm. Every day the weight was increased a little. When the weight got up to twenty-five pounds they stopped and gave me something else to do during that half hour. No one ever told me to try and raise the weight with my diaphragm; I guess I was supposed to figure that out for myself, which I didn't. Or the weight was supposed to make me breathe properly, which it didn't. So I went on with very shallow, uncontrolled breathing.

One of the other pieces of equipment that I used for a short time was the Elgin table. It had a pulley arrangement for each limb, on which varying weights could be added. A record was kept each day of the amount of weight that was pulled by each patient using this equipment. The amount of weight that I was able to pull increased very, very slowly, and I was soon taken off this program. A few times I was put down on the mats and tried out on the skateboard, but that didn't last long either.

They also tried a few times to put the probe from an electrical stimulation machine inside my mouth to touch an appropriate spot and make a muscle jump. Toward the end of my stay at Rancho I was started on a program of tongue exercises four times a day. A few times I was supposed to be given tongue exercises by trying to lick an ice cream cone. I managed to make a pretty good mess and have a mighty cold tongue.

About a month after my arrival at Rancho a man came by my bed and said they hoped to be able to fit me into their small speech therapy department. At this point I was still filled with hope by the tales of miracles that had been performed at Rancho. At long last, after many delays and much red tape, I finally had an appointment with a speech therapist, one who was also in a wheelchair. She filled out a lot of papers with my yes or no response to her questions and asked me to say ah.

Then she said that all our time was up, this had just been an evaluation, but we would work next week at the same time. The next week came and the appointment was canceled. The same thing happened the following week. The fourth week I went there by myself in the electric wheelchair. The first time I had been led to her office and I was sure I knew the way. But this time all the closed doors looked alike. I couldn't knock or ask questions so I waited a few minutes for the doors to open and then decided that it would be better if I went to find my O.T., and have her show me again just which door was the right one. So I, with my electric wheelchair in low gear, made my way two buildings away to O.T. She quickly got the picture and took me in high gear back to where I had been and showed me the proper door.

Whereupon the speech therapist said, "What are you doing here? Didn't you get the message that you were cancelled permanently because it would take too long to do you any good?" Later, when the speech therapist discovered that I was to go home soon she spent hours making up a chart with many different words on it, that I was to learn to point to quickly. As of this date, all subsequent nurses and my husband have refused to use this chart, on the theory, I

suppose, that if I get used to pointing, I will never try to talk.

This is an example of the kind of assistance that I got from Rancho. I'm sure that others who didn't present such a difficult problem benefited greatly from the time they spent there. The O.T. Department did make it possible for me to use the mobile arm support, but even that seemed to take much longer than necessary. Looking back on it, I'm very glad that episode in my life is over, but see, too, that it was necessary.

After I had my own mobile arm support, had it adjusted and had practiced eating with my gadget, I was sent to the dining room for lunch. The therapist in O.T. gave me the option of going to bed for the bedpan and to lie on my side for a while, or to stay up in the wheelchair through the entire day. I didn't think I could make it through the entire day, so chose the first course of action.

The nursing staff was to be informed of the new arrangement by O.T. It was supposed to start on a certain date. The nurses were trying to be very efficient and tried to send me to the dining room without going to bed first before the set date, and were quite put out with me because I wouldn't go. It was my understanding that the date was set so that the therapist could show the nursing staff all the idiosyncrasies of setting me up to eat. The next day I again went to O.T., very put out with the aides and nurses because they claimed I was stubborn and lazy. The first thing I did was to indicate that I wanted the typewriter. After I finally got set up to type I asked, "Just what is going on?" Between the typewriter and answering yes and no to many questions they finally understood me, and the therapist called up the nursing office and got things straightened out. The next time I saw the head nurse she apologized to me on behalf of the staff.

When the date arrived, I had a very tight schedule to get back to the ward in time to be put in bed for rest and the bedpan and then get up in time for lunch. Many times I had to sit and wait for the aides, since they were busy with another patient, so there was only time for the bedpan. But at least I was moved briefly off the sore bottom.

Then came the hardest part of the day: lunch! It took me the whole hour to eat, spill, and make a mess of lunch. The aides had been instructed to lift me halfway through lunch, but they claimed they didn't want to disturb me, so they wanted to wait until I was through. But I had a one o'clock appointment for P.T., and was warned to be on time, so at five of one I was headed for P.T. During the second half of lunch I wanted to eat faster so that I would be lifted, but I was so sore that I ate slower and never got lifted. So I arrived at P.T. very sore but with them believing that I had been lifted at 12:30. Sometimes they weren't open until ten minutes after one, and then it took a few more minutes before I was moved. Those were the longest few minutes of my life.

I was particularly disappointed whenever one particular daytime aide was assigned to my room. I appeared back from therapy at a few minutes after eleven to be put on the pan and on my side before lunch. But she didn't come right away. When she arrived, she said, "You don't need to go to bed, do you? There is very little time and you used the pan right after breakfast." I would be vigorously shaking my head, "Yes," as she was walking out the door not paying any attention to me. Now I had two hours to sit through before being "depressed". One time I tried

to reach my buzzer and ring it with my mobile arm support, but I couldn't get close enough to the cabinet that it was on and I had no way to lean forward. I had the problem of returning my hand to the control on the wheelchair, which was just barely within my reach. It was a real struggle. The next problem was: could I make it until 3 p.m. without wetting? Sometimes yes, sometimes no.

It was essential to keep the laughter under control on those days. That was not always possible as something hilarious was always happening in therapy.

When it was nearly time for me to leave the hospital, the therapists discovered that I had been sitting through lunch without being lifted. I had to ask them many times to lift me, and they couldn't understand why I couldn't wait a few minutes. That is what started all the trouble! My P.T. was particularly disgusted, because she had attended one of the nursing meetings especially to stress the importance of "depressing" me around 12:30. This seemed to be the straw that broke the camel's back between this therapist and the nursing staff. She consulted with her superior and they decided it should be brought to the attention of the nursing office. A little later on I was typing in O.T. My O.T. was not at the hospital that day and the head of the O.T. Department had set me up. My head nurse came in and asked if she could see me for a minute. So the head of O.T. took me down from the typewriter and got me started out the door, where I was met in the hall by a bevy of my most unfavorite aides, the head nurse, a nice black nurse, my P.T. and the head P.T. The head nurse proceeded to ask me why I was never around the ward in the daytime, and yet could run and tell the therapists what happened.

I tried to tell her that the therapists were the only people in the daytime who ever took time to listen to me, so naturally they were the only ones who heard what I had to say, and also that I only said things that were true and common knowledge. But, of course, I couldn't get all that out. Many cutting things to say flashed through my mind while outwardly I was wailing; partly because I was unable to express my thoughts and partly because I was very upset.

Besides, I had difficulty communicating with even one person and now I was faced with many people, all interrupting and interspersing their own thoughts. The O.T.'s and P.T.'s were busy trying to calm me down while the nursing staff was saying that they would forget all about this incident and would try to do better. All I had to do was come up to one of them if I needed help. The answer that flashed through my mind was, "I don't understand what all the fuss is about when all I want is to be depressed once a day at a time when I'm unable to move my chair, and this has already been discussed with you by my P.T."

The next day I expected help at the appropriate time. The time came and went and I was off for P.T., and still hadn't been "depressed". So nothing had been accomplished in the nursing department. I went through the final weeks knowing that I couldn't expect to be 'depressed' during lunch. After that the P.T.'s always asked me at once if I needed to be 'depressed'. So I had accomplished two things: a few minutes less discomfort for me, and more fuel for the fire raging between the P.T. Department and the nursing staff.

The day after the explosion my O.T. was in and heard about the ruckus. She told me

she found it almost impossible to believe. She had never heard of any of the Rancho staff holding encounters in the hail. My first reaction was to tell her that it was the first time I had ever been glad that I couldn't talk, since I surely would have said some things that I would've been sorry for later.

The O.T. decided that the only course of action left was to send me home as soon as possible. This sounded very good to me, especially since I felt trapped there against my will and the glow of hoping to be helped had worn off. So I asked my O.T. to call my husband. You see, I knew the difference in the amount of time it took him to accomplish anything and the snail's pace that Rancho took to go through all its red tape.

RANCHO WEEKENDS at HOME

I managed to go home every weekend, including the first one, during the four months that I spent at Rancho. I was glad to see the weekend come. Visiting home I could see my husband and children. The camping air mattress and two sleeping bags that I lay on in the back of our station wagon were much more comfortable than the hospital bed with a hand pumped hospital-type air mattress. All I had to worry about was the swaying of the back end of the car during the two-hour drive home. On a turn it felt exactly as if the car was going to roll over again. On this matter I forced my knowledge to rule my emotions. After all, I kept telling myself, I know who is doing the driving. I know what it feels like to be sitting in the front seat and feel the wheels solidly on the ground while the car is in motion. But forcing yourself to believe the opposite of what an emotion tells you is not an easy thing to do.

Whenever my children came along to bring me home for the weekend, I was able to divert my attention from the swaying by listening to their antics. On the occasions when they didn't come I wasn't able to transmit much information to Vic while he was driving. Whatever noise I was able to make didn't carry over the sound of the engine in freeway traffic. Vic devised a system of putting his hand on my forehead. This way he could feel whether I was shaking my head yes or no. Then he could spell or ask questions for me to answer. It was a very slow process and a lot more frustrating than either trying to spell or talk for myself. It was especially maddening to get to the last letter and have some traffic crisis arise for which Vic needed both hands. Usually, the last was the most important word. I used my system of putting the subject at the end of the sentence so that people would stop guessing and go off on a tangent. Or his arm would get a cramp or go to sleep and he'd have to move it. Then by the time the crisis was over or Vic had feeling back in his arm, he had forgotten what I said and I had to start all over again, probably to be stopped again just before the end.

There were so many things that must be done on weekends, with four children and a man to do them all. The trip home was frequently the last discussion time I had for the weekend. At least it served to distract my attention for a while from the swaying of the car. I could tell myself that this was just silliness and try to concentrate on practicing speech or trying to move muscles, but it was very difficult to concentrate on practicing during a swaying motion. One time I managed a devil-may-care attitude, and practiced from Downey to La Jolla. This too can be very discouraging, since I didn't see any fruits of my labor.

I was happy to be home at last, but that feeling soon turned to fear. The next operation was to get me into the house. This sounds simple enough but is quite involved. First I was unloaded into the wheelchair that had been tied to the baggage rack on the roof of the station wagon. Then came the insecure trip around the house, with me feeling like I was slipping out of the wheelchair or tipping over.

Finally, I was in the house. If the children had not been on the drive home it was time to let the housekeeper go home. I was not used to having a housekeeper. Having her hear information about family activities to come, when I was learning about them, too, for the first time, made me feel like an outsider and doubly resentful. Just trying to be nice to someone who is running your house is difficult enough, especially when you see things that in your day were new or in good condition and are now worn and grimy.

After the housekeeper left I was propped up on a sofa bed. It belonged in the family room, but had been moved into what was the long-awaited-for dining room, which had been converted to a bedroom for the housekeeper. This room has a folding wooden door opening onto the living room, so I was in the center of activities.

The bed, which once felt extremely comfortable, now felt like lying on a board and got harder with each passing minute. But there were many distractions. When dinnertime arrived, I was moved into the wheelchair again and taken to the kitchen to sit while dinner preparations were being made by father and small children. They did things that had my heart in my mouth, such as putting things into a hot oven with worn potholders, pouring liquids into an almost overflowing container, and of course, making the expected mess.

One difference that becomes sharply apparent between men and women is that men seem to be able to concentrate on only one thing at a time, but engross themselves very deeply in whatever has their attention. Women see many things happening at one time. They may not make as many important decisions, but avert more catastrophes. While father is answering one child's questions, three disasters can happen. Sometimes they get cleaned up before father is aware of what's going on around him. This provides very strong motivation for me to get up and do something, so I try. But all it produces is a spasm, which is interpreted by children as something being wrong with mother. This does catch father's attention and then everything comes to a halt until it is determined that nothing is the matter. So by the time dinner is on the table I am a nervous wreck and very sore on the bottom side.

The family seemed to eat very quickly. They'd be working on the cleanup while I was still choking down my food. I was sore where I should be numb. After dinner was finally over, it was usually decided to be more expedient to put me in the bedroom and prop me up there for a while. So down the hall I went and onto the bed. I'd have a moment of relief as I was lifted onto the bed, but then the soreness came again, gradually getting worse.

Then it was bedtime for children, and father was busy getting children to bed. The sound of running water for teeth brushing and toilets flushing is deadly for me. I'd have the feeling even more strongly that all I had to do was swing my legs over the side of the bed, sit up and walk to the bathroom. So, not thinking, I tried and nothing happened. So I tried to hold on until

things settled down and help came. Sometimes I made it, sometimes not, but I was always accused of being jealous of other people needing attention. It took many months before I realized I was being teased, partly so father could maintain his sanity.

Finally the last child was kissed and tucked in bed. Now should be the time for me to talk to father. But I'd held on as long as possible and was screaming for the bedpan. After I finally got it, no one understood why I was so upset over such a simple matter as needing the bedpan. Then it took me a long time to calm down. There were many things I wanted to talk about. All of them seemed equally important. It was impossible to discuss all the things I wanted to, so we usually ended up talking about nothing. Anyway, by this time Vic was busy preparing dessert for us. It's very difficult for him to figure out what I'm saying while he is eating, and difficult for me to talk while eating; it makes me choke. So time passed in one-sided conversation or silence. Another day went by and I was still wondering about many things. Then it was time for the adults to go to sleep. Vic was exhausted from the arduous day and went to sleep soon after hitting the pillow. I was usually wakeful for hours, despite medication. But I finally went to sleep.

After having to be turned several times during the night, I woke up early to a sleeping husband and sounds of very active children. My first impulse was to jump out of bed and quiet things down, but all that happened was one big spasm. Here I was lying in bed with a sleeping husband, who gets up too early every other morning, and who had been awakened several times during the night. I was torn between letting him sleep and preserving what was left of the house. Meanwhile, the children were having a ball with no adult around to spoil things for them. They had dry cereal and poured more on the floor than in the bowl. They ate, then left everything including spilled milk, open boxes of cereal and dirty dishes just where they finished. They reveled in watching T.V., eating and drinking whatever they could find in the refrigerator, spilling and trying to clean up. So there was a mess not only in the kitchen and family room, but also in the refrigerator. And every available towel and dishcloth had been used. All this was going on amongst squabbling children.

I decided the damage had already been done, so there was no point in waking my husband. Anyway, he was too sleepy to care, and this had apparently been happening on Saturdays for many months. So I lay quietly another couple of hours, in fear both of what was going on and of wetting to add to the general confusion. All the time I was trying to keep my mind off of my parched throat. Then came a light tap, tap, tap at our door and a little voice says, "Daddy, can Larry make waffles?" Vic woke up long enough to think for a few seconds, say, "Yes," and went back to sleep. Larry, who was nine when the operation occurred, had learned to make waffles, but always with an adult present. So another shot of adrenalin went through me thinking of all the things that could happen. But, this had probably been happening for quite some time. He made the waffles all right with no disasters, except for the dripping batter and sticky syrup that ended up all over everything.

Finally about 11 a.m. Vic decided he had enough sleep to face the day, so he got up and dressed. By this time the children discovered that he was up and they literally descended on both of us. This ordinarily would make me very happy, but I was still holding on for dear life so I wouldn't wet the bed, while children were unintentionally jarring me and the bed. My throat was

still dry and I was stiff as a board. Finally after what seemed like an eternity, my needs were taken care of. Now I still couldn't get dressed and up. The water seemed to push more liquid out, and I was afraid of wetting my clothes, so I had to stay in bed and wait for the next pan time.

After that my slacks were unceremoniously put on, complete with legs going plop on the bed. Then I was transferred to the wheelchair to get my blouse on. Vic usually transferred me by pulling me erect in a bear hug. Sometimes I stood on a foot bent in the wrong direction or scraped an ankle on the metal frame of the bed. If I yelled, it only delayed putting on my blouse. With no sling under me, my bare back rested against the ice-cold back of the wheel chair. Then my shoes were put on and my feet placed on the footrests. The right leg usually shook out of control, so someone had to lean on my knee to stop it.

Then I went out to the other part of the house to have some eggs. This experience is a chore, but is much more pleasant than eating cereal in the hospital. By now the children, who had been eating all morning, declared that it's time for lunch. So while Vic and I were having breakfast, children were fixing themselves a sandwich and attempting to clean up at the same time. When either the sandwich was ready or the dishwasher was full, all attempts to clean ceased. The dishwasher is expected to do a fantastic job, because all dishes are put in as is. When the dishes come out, if they are dirty that's all right. It's sanitary dirt. When the combination meal was finished, everyone left the kitchen for other activities. The practice seems to be "never clean up until you need the space for the next meal."

As the afternoon passed I got very sore from sitting, but was determined not to ask for help. In the hospital everything is done on a schedule; I wasn't accustomed to asking for help; it's better to wait for the schedule. At home I got more and more sore as the time passed. Finally I had to lower my pride, forget about past independence, and ask for help. I still had to wait for an opportunity. I thought the proper time was when there was a few seconds lull in father's activities. But apparently my timing was not very good. I'd hear, "Just a minute," or "You have a genius for needing help at the wrong time." If I got upset, it arose from a combination of needing help, being very sore and the answer I received, but the upset was attributed to impatience.

This occurred several times during the afternoon, so I usually ended up in bed for a rest while dinner was being prepared. At this point, father looked in the refrigerator to see what the housekeeper had left. All problems were met as they occurred. Planning ahead was a thing of the past. If it did occur, it was a well-kept secret. The table was set from the dishes in the dishwasher; then the rest of the dishes had to be emptied so the kitchen cleanup could continue simultaneously with dinner preparation. There was general confusion at all times whenever anyone was working in the kitchen. Each person was given a specific job to do, but the children seemed to find many other things to catch their attention. Everything came out all right, despite several catastrophes, and all but the floor was reasonably well cleaned up after dinner. Of course, anything they couldn't find a place for was left on the counter. There was a general air of clutter.

The children were receiving training all right, but it was quite different from what I once had in mind. For instance, they have become accustomed to my explosive coughing spells when

I eat. It's quite usual to see four small people disappear under the table at the onset of a spell. Then after a few seconds a little voice says, "Is it safe now?" This looks hilarious. It's really quite practical, because I have very much difficulty in swallowing and almost anything can cause a coughing spell—especially a tiny grain of food slipping into my windpipe.

After dinner was over I was usually exhausted from coughing and trying to feed myself with the aid of the new mobile arm support, so I was put back to bed. The burning sensation that goes with sitting on my bottom was always with me. Sometimes we gave it a rest by laying me on my side propped up with the always-useful pillows. Soon it was time for children to go to bed. With the deadly sound of running water, the last night's procedure was repeated. Then it was once more time for an exhausted father to go out like a light.

After he turned me several times during the night, Vic would wake up to the sound of an alarm. There was church to attend with a choir for him to direct. I was once a member of the choir, and it felt very strange to be home and not getting ready on a Sunday morning. Now came a bad time indeed. After breakfast, Vic took all the children off to church school and returned in a very few minutes. For those moments I was left alone, tied into the wheelchair so I wouldn't land on my nose with no one around to pick up the pieces. That seemed to be a good time to yell. The only trouble was once I got started it was hard to turn off. I was usually still getting it out of my system when suddenly the door opened and there Vic was again.

A few minutes later it was time for Vic to go after one of the three older children to stay at home with me during church. This was another bad time. I was put into bed and on the bedpan before Vic left, but this was morning. A little over an hour with no one strong enough to move me and put me on the bedpan was a long while. Trying to stay dry for that long was quite a trial. Time seemed to stand still. I could vow I wasn't even going to think about the subject, but the warning signals came, and it took all my concentration just to tighten up on those muscles.

Sometimes I concentrated hard enough, sometimes not. Then when the troops did come marching in, there were five people all talking, and it was very difficult to make my weak "pan" heard over the turmoil. Sometimes it's necessary for me to get angry before I have enough breath to make myself heard. The speech therapist tells me that emotions are the seat of deep breathing, but so far it's not possible for me to talk during any emotion except anger. She keeps working for an enthusiastic, positive, vital sound. I can get pretty angry when I feel reasonably happy but can't make a sound.

Finally someone gets the picture. Then they quickly do their own jobs. One pulls down the covers, one runs for the pan while Vic is turning me over, and still another one is helping to get all clothes out of the way. It looked like pandemonium, but actually each person knew exactly what to do. Still it looked amusing, but I must not laugh until I was plopped on the hard, steel pan. That hurt, so I was laughing and crying at the same time.

This, of course, ended forever any chatter about the morning at church. If I asked any questions, no matter what they were, I heard, "Was that really so important to take that much time to ask that?" So I stopped asking any questions and started eavesdropping on all

conversations. I was intellectually and socially starved, I was supposed to do nothing but practice, practice, but not make anyone (especially the children) think I was talking to them. Constant practicing was difficult for two reasons. It was hard to admit to myself, but I did get very tired just from even trying anything. In my mind I was doing these things with ease while my head raced with other thoughts.

Soon it was lunchtime. Life seemed to be filled with mealtimes (a necessary evil), football or baseball games on T.V. (which I detest), and a sore body (no matter how I lie or sit). Sunday afternoon wore on and soon it was time for the dreaded cock-eyed ride. It took several hours. We always hit the Sunday traffic jam. Back to Rancho and another five days work to do before I could come home again. Five more days of scheduled torture and then I might return to my obviously deteriorating household and garden.

Each week I felt that things were more and more hopeless as the weeds grew taller, the children's bikes got rustier, the kitchen floor got darker, the upholstery got shabbier, the rug got dirtier and the children grew taller and wilder. All the time I was hearing about what a wonderful housekeeper we had. I decided they must be talking about her personality, or her cooking. I had the feeling that once I got home I would be well and able to cope with the situation. But for the time being, I might just as well grin and bear it.

Back to work at the hospital. All the hospital frustrations were still waiting for me. The same aides were handling me in different ways, some better than others, some nice, some not so nice, some just not caring, and some just plain mean. And no choice of anything, especially from those who don't care and those who are just plain mean, but in a way I could understand. The hospital was short of help and this was the aides' way of finding shortcuts, so that they might have a leisurely lunch and their coffee breaks.

HOSPITAL DISCHARGE

Before I left Rancho I had to appear before a panel of doctors while my P.T. told of all the great and wonderful improvements that I had made since I came to Rancho. She told of things that I could do now that I couldn't do when she first saw me. In my own mind I disagreed violently with many of the things that were described about me to this battery of strange doctors, but I wouldn't have openly disagreed with her even if I could speak. I was not about to jeopardize my chance to leave this scheduled misery. I think the therapist was very sincere in her belief of all the things she was saying about me. They were all things that I had heard her say before, and didn't have the energy to correct, believing that it didn't matter anyway. A great many of the things she was describing were things that I could do on entering Rancho, but was too scared and nervous to perform for a strange audience.

In anticipation of my going home, we asked my former day nurse, Jean, if she would like to be my nurse at home. She was afraid the repeated lifting might be too much strain on her shoulders, so she recommended Mrs. Curtis, who came and spent two full days with me at Rancho to learn about my program. We got along very well right from the start. It's a very uncomfortable feeling to have someone, especially a stranger, watching you every minute, and following you around all day. The thought of going home seemed strange. I had pictured myself

going out of the hospital on my feet and not in a wheelchair. I was sorry to be leaving the therapists, but happy to be leaving even the best aides, nurses and technicians.

At long last I was discharged from the hospital. Staying there the last few days, after I knew I was to be discharged, was quite a trial, but I kept telling myself I could stand anything now. How could it get worse?

HOME at LAST: SUMMER 1967

So here I am, home at last. While spending ten months in three different hospitals I thought coming home for good was next to impossible. Now it's frustrating to be here and be totally dependent on the help of a nurse and a housekeeper, but it's better than being dependent on strangers in unfamiliar surroundings. I have weak use of my left forearm and hand and I can wiggle my left toes a bit. My head will turn from side to side as far as the spinal fusion will allow. My eyelids seem to be under control. It feels like my facial expressions are normal but the mirror tells me something different. I can only make very soft sounds, from which people have to guess what letter and word I'm trying to say.

Here I am, but what can I do to start managing the household again? I told the therapist at the last hospital that the housekeeper could run the kitchen and I would worry about the children. That seems hard to accomplish right now. I feel pretty useless.

My nurse, Mrs. Curtis, doesn't need to ask me how to solve any problems that come up. She works with me eight hours a day, five days a week. She's very competent and experienced in all phases of nursing. In a friendly, inoffensive manner she radiates confidence in her ability to handle any situation.

We also have a housekeeper who lives in the house five days a week. Since this is my first experience with housekeepers, I don't quite know what to expect. Iris is the fourth housekeeper we've had in the few weeks I've been home.

I quickly built up quite a resentment towards the first one. For a while, I thought this feeling stemmed completely from having another person in my place and tried to tolerate the situation. I soon found out that the rest of the family had their own complaints. She didn't try to understand me at all and I lived in great fear of the time when Vic would be out of town and I would be alone with her for the night. As it turned out, she had no desire to learn to take care of me at night so when Vic was gone for the night, Mrs. Curtis stayed. That was a very expensive way of life.

My strong resentment towards the first housekeeper was enhanced by some of her charming habits, such as entering the bedroom without knocking when the door was closed. The door was open most of the day, but she always picked the short time when it was closed to come in to put clothes away. Then there was the time she put a cigarette burn on the one really nice piece of furniture we had. She got the job by promising in the interview that she would do all her smoking outdoors and not smell up the house. When she went shopping for the household she even considered it proper to purchase cigarettes from household money. She made other

purchases that I might have approved, had she asked. Instead she said with a sullen attitude, “I have to have some conveniences in order to be able to work.” She made the purchases and then proudly showed them to me. I suppose it’s a good thing my face didn’t reveal my emotions, because the colors and patterns of those purchases weren’t what I would have chosen. In fact, they often clashed with the interior decorations of the house.

I repeatedly typed notes to her asking her to not use so much pepper in the food. When I finally succeeded, we discovered that the food had also been over salted.

When she demanded a new mattress for a sofa bed that we considered to be as comfortable as our own bed, Vic decided that she wouldn’t work out. He must have been quite dissatisfied, because he let her go after three weeks with a three-week gap to be filled in before Iris could join us. The three weeks were planned to be filled in by an elderly lady who had had a nervous breakdown and was very shaky. She was with us for only a week. Everything she cooked tasted the same and looked very soupy and thin.

Then we found a nice middle-aged lady who acted more like a “nanny” to the children than a housekeeper. She was only available for one week. Perhaps that was a fortunate thing. She was the “Oh, you poor dear” type. By the end of that one week I had been driven nearly crazy and I really exploded.

Mrs. Curtis handled the third week alone. Ladies from the church came in at four o’clock when she left and stayed until after six o’clock, when Vic arrived home.

Now we have a more permanent housekeeper, whom I will call Iris. She has some unfortunate traits, but seems to be much better than what we have survived. Foremost among her good traits is that she’s always cheerful. After three weeks of sullen looks from the first one, this seems very important.

Iris never knowingly goes against my wishes, but is usually too busy to find out the facts. The simplest procedure seems to be just to let her follow her own inclinations. Even if I could communicate in a normal manner I’d have a difficult time in conveying ideas to her. This took some time to learn. At first it seemed to me that everyone agreed with anything she said or did, and it made me feel even more alone than the lack of communication had already made me feel. Then, slowly the realization came to me that others are trying to be subtle and polite in expressing themselves, but it’s all going over her head.

Fortunately, these traits go along with a different kind of sense of humor than I have ever encountered, and I spend too much time laughing with her to be too terribly frustrated. She is a rather remarkable person. She has recovered from cancer (what kind, I don’t know) and it has left her blind in one eye and deaf in one ear and with a high calcium deposit in one nostril. She was formerly a schoolteacher, but her poor eyesight now makes it impossible for her to teach. She’s always telling how wonderful her grown children are (as most mothers do).

I thought a former schoolteacher, with grown children who had turned out well, would be good for my children. She is a good example, because she’s normally very cheerful and happy

when working around the house, but she's short-tempered with the boys and occasionally becomes vexed with the girls. She believes that the boys are old enough to be told something once and then they should mind, and she is then through with the problem.

Normally, she might be right, but these children have been taken care of by at least six other people before her and are smart enough to know which people they had better mind and which people they can take advantage of. When they don't obey she sometimes screams at them, and sometimes does nothing but report to me about how badly she has been treated. When Vic is home everything is peaches and cream, because the children have a healthy respect for him and behave quite reasonably in his presence. She may calmly mention that the children have not behaved properly, but she reserves her ranting and raving and screaming for times when he is gone overnight, or after the nurse has gone and before Vic comes home.

Sometimes it gets to be very amusing when she deliberately leaves some problem, hoping Vic will notice. Unless it's pointed out to him, he appears oblivious. There is much on his mind. When things become too bad, I have no other recourse than to bring my grievances to Vic. So, I seem like an old grouch with a cheerful, happy housekeeper who handles a hard job with ease.

The children soon learned that they had better not misbehave in the presence of Mrs. Curtis. Yet she is always doing nice things for them. They have learned to love and respect each other. Iris' version is that Mrs. Curtis is jealous of her authority over the children. There is a form of jealousy existing here, but it's not experienced by the nurse. It is mine. I have a sort of sinking feeling each time a child has to be taken to the doctor, to school, or to a lesson of some kind, and I'm not doing the taking.

Communication is my most difficult problem. I have no voluntary control over my breathing, so I can't hold or expel air forcefully to make sounds. People have to guess from the position of my lips and the faint sounds I make what letter or word I'm trying to say. It takes a long time to put any information across that way. I have learned to use an electric typewriter, but it requires my arm to be placed in a support mounted on the bed or wheelchair. The aid of rubber bands and ball bearings enables my weak muscles to type with one finger, about one letter per second. This book was written that way.

I move about the house in a battery-powered wheelchair. My nurse transfers me between the bed and wheelchair using a hydraulic lift.

I eat foods that have been pureed, usually with a blender. I can chew a little, but my tongue isn't able to keep pieces of food out of my throat, where they choke me. Even my swallowing occurs more by reflex than deliberately.

I drink by sucking on a straw. Thin liquids, like water or coffee, tend to drip into my windpipe and produce coughing. I prefer the taste of coffee, but I'm forced to settle for chocolate milk or tomato juice.

Fortunately, I do have barely enough control over my urination not to need a catheter. But when I say, "Pan," (for bedpan), somebody better move fast.

Sitting or lying in one position for a long time without moving any muscles hurts. The points where my weight is concentrated soon ache and eventually would become painful sores if I'm not moved regularly. Air filled pads are a real help: they distribute my weight more evenly. We also have a pad with two interleaved sets of cells that are inflated alternately by a pump. This way the pressure points are continually moved. I still need to be turned from my back to each side when I'm in bed, or to be lifted for a few seconds when I sit in the wheelchair.

LIFE at HOME: ONE YEAR LATER

When I was in the hospital I said to myself, "I'll be content just to be at home watching the children grow." Now that's not enough. It's an extra frustration to watch my children walk around with shoelaces untied, buttons unbuttoned, socks and collars not folded down, cuffs not folded up, hair never combed, and wearing colors that don't go together. Iris, who is in charge of the children, says in their presence that she has too much work to do to help them. In turn, my own children tell me that it doesn't matter how they look when they are only playing.

I suppose this happens to all mothers, but it really seems like a big thing since I can't explain my position, and meanwhile the children are growing up with completely different training than I wish.

Iris set about trying to win the affection of the children before she would discipline them. Meanwhile, I was looking for a way I could effectively punish them for wrongdoing. One way was to deny them a trip to the beach that they had requested. When the children couldn't get what they wanted from me, they tried Iris. In her exuberance to win their affection she agreed to take them, if I would give my permission. They were all very enthusiastic about the outing, but I had to appear mean and say, "No." So we didn't get off to a rousing start, but several weeks later they had their day at the beach.

I want the housekeeper to be friendly with the children, but it was difficult not to be very startled when the children reported that they were making Mother's Day gifts at school and that they intended to give them to the housekeeper. Much later, after someone must have told the children to give the gifts to mother, I understood that their intentions were quite reasonable. The gifts were such that they would be used by the housekeeper.

When Vic is out of town everyone else usually spends the evening watching television in my bedroom. In a way this is nice because the nurse and housekeeper very skillfully manage to keep the children away from me during the day. Even at my lunchtime, when I go out to the kitchen and living room in my wheelchair, there are no children in sight.

Anyway, I see the children while they're watching television. I also want to talk to them, but decide it's better to wait for a commercial, both out of consideration for the child and as a teaching-by-example tactic. A commercial comes along and I call the child. The child says, "Wait a minute, I want to see this." The child appears after the commercial is over and the program has started. This happens repeatedly, and I conclude that the commercials are more important to the child than the program, although both seem enthralling to him. Now what do I

do? The only time they're around they don't wish to be interrupted. And what has happened to my idea of teaching by example?

Even though they're watching television there is still some chatter from them. That is, if they're not being shushed by Iris. She's heard their chatter all day and is ready for peace and quiet. Through their chatter I learn of various activities that have happened, good and bad, both occurrences that Iris would just as soon I didn't know and things she considers unimportant. But they all are factors in decision making in a household.

There are times when I hear a child say, "Just a minute," and I wait and wait and no one shows up. Suddenly I discover that this is happening mostly with our second boy, Kenny. He's the same boy who can't pick up my spelling while his younger sister, Linda, has become quite adept at it. Her problem is that she has to run and ask someone what many of the words mean.

Kenny is the family comic and jokes about how I say the letters. He's quite funny and uses this fact to get me laughing and then it's impossible to talk. After this happens many times we're both laughing at his antics. Then, I'm frustrated because I can never make him finish what he started out to do. Kenny is good at guessing what I'm saying. This is wonderful until he is completely on the wrong track, but convinced that he's right.

Not only is this extremely frustrating to me, but at the same time he's learning impatience, because it's almost impossible to get him back on the track. Kenny also enjoys gadgeteering. With his good personality and uncanny ability to repair things he becomes the darling of every live-in person.

Unfortunately, too many of them expect both boys to be alike and are forever chiding our older boy, Larry, for not being like his brother. Larry loves activity and has all sorts of plans, while Kenny enjoys tinkering by himself at home. Kenny also has the ability to get into more mischief than Larry and yet make it appear as if he were very good.

The children and Iris both know that the children aren't supposed to ride their bikes in the street. But apparently they do it anyway, because each child comes to me and tattles on the others. I'm sorry they are really learning to tattle on each other, but I have no other way of knowing about what's happening. After the children tattle, Iris puts in a word on the validity of what I'm told, adding the fact that the children know it to be wrong and if they insist on doing wrong she can't stop them. All this only leads me to the conclusion that things are going on that I don't know about. I only find out when someone happens to tattle on another, and no one is putting a stop to it. So I live with fear and feel many pangs each time I hear a car go screeching by.

The children know that they're supposed to be in by dark, but this rule is not enforced either. They have started staying out later and later, and one evening Larry didn't come home until hours after dark. I was very worried and I suppose the housekeeper was too, but all I heard was how she was going to have to have an understanding with that boy. I thought I had an understanding with him from the beginning, but now I know the rules aren't being enforced. But my hands are tied. I can't afford to hurt Iris' feelings and have her walk out the door. My

worrying is about boyish naughtiness, and I'm full of tense, tight nerves trying to look calm.

All this time the children are growing up with the idea that they don't need to follow the advice of the person in charge of them. This is going on at the same time that Vic is having business problems and the greater part of his thoughts are on his work. So I've tried, without much success, to tell myself that I'm borrowing trouble just because Vic has problems.

Even friendly instructions turn into disasters; what would happen if I tried what I consider to be constructive criticisms? Once I felt especially frustrated with the problems. We were having to throw out food that was too old and starting to turn rancid. I typed out what I considered to be a fairly mild criticism. I never gave it to Iris, because Vic read it first and misunderstood the meaning without knowing the circumstances. I figured that if he misunderstood my intentions, then I could only cause all kinds of problems with Iris. Fortunately, the problems with the rancid food cleared up. I'm never sure how she would handle the other problems anyway.

A few weeks after Iris joined us I discovered that Vic was having serious difficulties with some of the men who worked with him. A number of them had decided to leave and go into competition with him. To make up for their deficit in work and try to salvage something of what they had been doing, he had to work many hours a week. He left very early in the morning and worked until about an hour before bedtime. He also put in a full day on Saturday. He only took off a few hours each week to direct choir practice. This meant that when he was home he was extremely tired.

What did this mean to me? After a few minutes to unwind he got involved in watching a T. V. program. That didn't seem to be a proper time to try to communicate. When the program was over Vic dashed off to the kitchen to fix our bedtime snacks. I had specific instructions not to try to talk while eating, because then I am completely unintelligible and choke a lot. It's a great temptation to talk when he finally has a chance to sit down. Next come the preparations for going to bed, the transfer from one bed to another, stuffing pillows in the proper places and tucking me in. At last Vic could lie down and I tried to talk, but he fell asleep.

Then I thought, "I'll try again tomorrow." The next day a variation of the same thing happened all over again. So I tried typing notes. That was even more frustrating. I used all my book-typing time on this one-sided conversation, which he read very quickly. His answer usually sparked me to say something else, but I couldn't. Solution still pending. Result: frustration and no communication.

Iris gave me a lecture once that sticks in my mind, perhaps because I disagreed violently. She said, "Don't concern yourself with the bringing up of the children. Spend your time concentrating on making yourself well." Her contention was that they would grow up whether I was there or not. I wanted to answer, "As long as I'm here I intend to have some impact on the manner in which they are brought up," but I didn't get the chance and once again I felt as if she thought I was in complete accord. I may not be reporting her feelings accurately, but I'm reporting the feeling that came across to me.

One time Linda got a very serious lecture because both she and Kenny had forgotten to take their milk money to school. Linda borrowed 6 cents from the school office (which has a fund for just such occasions). Kenny went without milk and drank water. The following day Linda requested twelve cents so that she could repay her loan and have milk. This is where the trouble started. She was told that Kenny had done the right thing and she had to have my permission to get the twelve cents. I would have asked Kenny why he hadn't borrowed from the milk fund. In fact on a similar occasion Linda had borrowed from the milk fund previously, and she must have been confused as to why the housekeeper was so angry. She was given the money and told never to ask for it again. Fortunately, that didn't stop her.

One day Iris did not feel well and went to lie down for a short time. Mrs. Curtis was genuinely concerned about her and went to find her to see if there was something she could do. I was worried too, and asked Mrs. Curtis about Iris. The nurse assured me that Iris was fine; she was even up and working again. Later on I received a tirade from Iris that went something like this: "I hope you know that I'm putting my time in. When I went to lie down I really didn't feel well." She had gotten up because that nosy nurse had come checking on her.

In a way Iris is a very particular person too. She insists on doing things that I gave up long ago, such as pressing pillowcases and drying silverware after it comes out of the dishwasher. She considers these things to be essential and yet lets everyone know (very pleasantly) how much work there is to do. I am a little upset most of the time because she finds time to press pillowcases but not to sew on buttons, unless specifically directed. I think it's common practice to check for mending as the laundry is done, but not so with this housekeeper.

Iris has only one good eye and has a terrible time threading the sewing machine, so Mrs. Curtis gets it all set for her and even helps her sew when she has time. But Iris still has a terrible time and is constantly breaking the thread. She claims the machine has a personality and doesn't like her. This machine has two settings when you raise the presser foot. The first setting keeps the thread under tension and the second setting releases the tension. We discovered that she was only raising the presser foot to the first setting and we tried to explain this to her, but she's still convinced that the machine is against her. The machine was creaking and groaning, so Mrs. Curtis oiled it and had it running very smoothly, but it continued to break threads for Iris. So whenever at all possible, she simply avoids mending. It's pretty frustrating to see my children running around in rags.

Some of the clothing has gotten down to no buttons at all. This is especially frustrating when I know that the machine can sew on a button in a few seconds when set properly. Oh well, when they do have buttons they aren't used, the little children can't manage them and the older children say, "It doesn't matter how we look."

I asked Iris to let down the hems in some dresses for my youngest daughter, Karen. She agreed, but asked me to gather together the specific dresses. This took a few days for me to accomplish. In the meantime Iris told me, "Since it's near the beginning of summer I've decided to leave the dresses alone." She considers it to be cute for a little girl to have her buttocks showing. So I continued to make my collection of short dresses, including one that she had just shortened, and confronted Mrs. Curtis with my dilemma. She told me that she knew it would

make Iris angry, but she would take the dresses home and sew them. Some of the dresses required false hems in order to make them long enough. This way they were just slightly long. I considered this to be just fine, because summer seems to be a period of great growth. My older daughter, Linda, seems to have skipped a size in her growth. Otherwise, I'll have to buy new dresses for Karen. Well, Iris did get angry, but only showed it by telling Karen that her dresses were much too long. So Karen was torn between gratitude to the nurse and loyalty to the housekeeper. There was another factor involved in Karen's decision. She wanted very much to grow up and be a big girl, so the long dresses won out over the too-short dresses.

One day Karen got all dressed up for school in a blue skirt, a white blouse, and a turquoise sweater. Well, I thought, that combination is bad enough around the house, but I just can't let her go to school that way, even if I do go against the wishes of a sensitive person. So I asked Linda to ask Karen to change her sweater. I didn't specify the color. Anything else she had would be an improvement. She came up with a little red sweater and asked me if that was all right, to which I replied, "Yes," being very relieved that she'd changed. In the meantime Iris was getting dressed. It was her turn to drive the car pool. When she came to get Karen she demanded to know why Karen had changed her sweater. Karen answered, "Mommy told me to wear this one." Iris didn't have any extra time, so she took Karen's hand and left with a parting remark, "Well, all right if you want her to look like a flag."

Apparently my eyesight is better than Iris' when things are at a reasonable distance, because I can see many things that irritate me. Some of them are things that I can have Linda change on the weekends and others are constant frustrations. The things that are corrected always seem to end up back to the way they were. But, of course, with so many people in the house that could have been done by anyone. There are little annoyances that everyone but me consider unimportant, such as all the lampshades facing the wrong direction. They are things that I would normally take care of, but they seem silly when you have to ask someone else to do them. But, somehow these little annoyances are difficult to ignore. Or I see the same dirty spot on the vertical surface of the kitchen tile week after week, and finally get annoyed enough to ask Linda to wipe it away. Being constantly in a sitting position and not always rushing around, I suppose these things are much more noticeable to me.

Iris is very neat and clean wherever the dirt shows easily, but doesn't, to my knowledge, move any furniture. In my bedroom there is a portable television set that has feet that raise it up about an inch above the table it rests on. Dust tends to collect in this gap and shows, but it's not easily accessible. Day after day the bedroom is cleaned up and this spot sticks out like a sore thumb, but I don't say anything about it. One day, after several months, Mrs. Curtis said, "I can't stand it anymore." With one hand she quickly lifted the portable T.V., and with the other dusted under it with the dirty towel she was holding. It all happened so fast that at first I couldn't understand what was disturbing her. Well, then I knew that it bothered someone besides me. Now a few more months have slipped by and the spot is very dusty again. This time it was I who lost patience first, and I asked the nurse to do the same again. She certainly figured out the sentence in record time.

Iris is a fine person and gives very good advice to the children. She is a hard worker, but she spoils her good qualities by extolling her virtues. She claims some that I wouldn't call

virtues. One evening she spent quite a lot of time telling me that she was doing the nurse's work, but she was happy to do so as long as she could get her own work done. At first I didn't understand. Then it came out; she thought that she was doing the nurse's work when she dusted the hospital bed.

When Iris was first with me, I had her go through some children's clothing with me. It had to be done in the evening since we were both busy in the daytime. The clothing was in a terrible state: it hadn't been sorted for a year, and children have a habit of growing. Also, many hand-me-downs had been given to them in the meantime. I had no idea what they had. After a few evenings of sorting about once a week, Iris let me and the children know, "I'm doing this work out of the goodness of my heart. I work hard all day and really earn my salary." Not knowing what to expect from a housekeeper, I thought perhaps this was beyond the call of duty. From then on I had the children help me on weekends. This, of course, takes an infinite amount of patience (which I don't have) since it takes much longer. Also I have to let the children's resentment bounce off and say nothing. We have now cleaned many cupboards and closets in this manner.

Iris really has my best interests at heart. One time I remember very clearly having tears that I didn't want anyone to see. The tears were caused by my daughter. I was used to children squeezing themselves next to my wheelchair in the narrow hall to get in front of me, and I was used to being teased by adults about always being in the way, but I wasn't quite prepared for my daughter's exasperated, "Oh, Mother, get out of the way. Can't you ever do anything right?" That statement hit my sob trigger. The housekeeper wiped my eyes and made jokes and no one else ever knew the difference that time.

I get along very well with Mrs. Curtis. We put up with each others' idiosyncrasies. We both know that we are particular people, and quite a few of our idiosyncrasies overlap. I must admit there were a few times when one or the other of us became quite annoyed with the other. I may not be aware of all the incidents, because Mrs. Curtis is a master at hiding her true feelings when the occasion calls for it. I was never too good at hiding my feelings. With brain damage, it's impossible. She is forever telling me, "Put your mind to it, put your mind to it, you can do anything if you just put your mind to it." I let this go by. I keep telling myself, "Remember, your paralyzed facial expression doesn't reveal how hard you're trying to make the necessary nerve connections, and it does look as if you aren't trying." I'm a little annoyed, but I can express myself while practicing the speech lessons. Perhaps I can add a few choice words of my own that can't be understood anyway. For all I know this may be what she had in mind.

Then there was the time when Mrs. Curtis was visibly annoyed with me. She had a little extra time, which she used to open some nightgowns all the way, instead of just having a short opening at the neck of the gown. This necessitated some sewing, which she did very neatly. Then she wanted to put gripper snappers on the new opening. She had put on grippers before, but had always used a special tool that I didn't have. So she asked me, "How have you applied them?" I replied, "With an empty spool, the gadget that comes in the package and a hammer." She had the kitchen table all padded with newspaper and a block of wood and was ready to hammer when I saw and stopped her. I was worried about what the pounding would do to the floor. She assured me, "I've protected the table. Where did you apply grippers?" I replied, "On

the steps to the garage.” She picked up the hammer and the sewing and said, “I think I’ll go out on the back patio in the sun.” I had the distinct feeling that she was taking a walk to cool off. This was the first time I had dared to oppose her ideas and she didn’t like it one little bit, especially in the presence of the housekeeper.

When I first came home from the hospital the bathroom cabinets were full of stuff. They had been fairly empty when I left. There was an accumulation of things that had been there before, and many things that must have been left by my sister and the various housekeepers. Mrs. Curtis took out everything and rearranged it to her satisfaction, so that she would know what was there to work with and to find out what was needed. This was fine with me, since the bathroom door was too narrow for me to fit through. Anyway every cabinet in the house needed cleaning out and it took a lot of time and much frustration to train my six-year-old daughter to help me.

Sometime later Vic widened the bathroom doorway, so I could finally get my wheelchair into the bathroom and be close enough to the cabinets to see what was in them. I know pretty well what is used and what sits there just taking up valuable space. Of course, no two people ever arrange anything exactly the same way. There were several items cluttering up the bathroom that I thought should be kept in the cabinet. I rearranged the bathroom to my satisfaction, taking into account the things I knew were needed. We have a rule in our house that anything that’s not labeled goes out. I found one such bottle and out it went, along with a tube that was squeezed completely empty. To me the bathroom looked much nicer than it had for nearly a year.

Unfortunately, it didn’t last long. When Mrs. Curtis came in on the following Monday morning the fur did fly. Many of the things that I had put into the cabinet were pulled out and put back in the place where they had come from. The bathroom took on its cluttered look again. She was furious with me, saying, “June van Lint, I could just kill you.”

That afternoon I had my son retrieve the lost items and label the bottle. The nurse said, “Oh, you didn’t have to do that.” I wasn’t sure which she meant, retrieving the items or labeling the bottle. She claimed that it was not necessary for the bottle to be identified; she knew what it was and she was the only one who used it. So I found out in no uncertain terms that as long as she was here I didn’t have the right to arrange my own bathroom in my way.

Iris is a very neat person whenever things are out in the open, but very good at hiding things in the strangest places. Mrs. Curtis is different. She’s also neat and clean, and not only where it shows. In fact she seems neater about storage than about things that are used for a few minutes each day. She likes to have things that are used each day out in the open and easily available, and if anything gets moved she becomes very disturbed. But with so many people in the household, she has learned to be philosophical about misplaced items, and finds it faster to look than to ask. I’m a combination of both attitudes. I like to have things neat and clean both in the cabinets and out in the open. Therefore, I feel both akin to and a frustration with each person.

I thought I had a wonderful check and balance system between the children, because they

made it up themselves one weekend when Dad was busy in another room. They decided to have the boys inspect the girls' room and vice versa. I tried it one day when the children knew Dad wasn't around and it almost ended in disaster. The boys tormented the girls, and the girls cried and rationalized away whatever they didn't care to do. The only way out was to separate them. The girls cry very convincingly and the boys are masters of torment so it is rather impossible to sympathize with either sex. It's miraculous how traits of sex show up very early in life and persist for a lifetime. Well, that didn't work, but I have to think of something. I'll probably keep trying until they have all grown up and still be looking for a solution.

Mrs. Curtis and Iris both have strong personalities. The housekeeper is extremely sensitive, the nurse is not. During the five days a week that they are here I almost feel as if the house belongs to them, although I am sure neither one wants me to feel this way, or is even aware of my feelings. I resent having anyone rummaging around in my cupboards, and especially rearranging them. Logically, I know that no two women like to have a kitchen arranged the same way, and the housekeeper has to work there, but emotionally I don't like it. It's quite a fight to let logic win over emotion. I resent being called "my patient" by the nurse, although logically that's exactly what I am. Mrs. Curtis informed my children in my hearing that medically I am hers and have to do what she says. Logically this is true but emotionally it doesn't sit very well.

Anyway we are going to make some changes. The insurance is about to stop paying for part of the nurse's salary, so we have to get someone who doesn't earn as much as an R.N. While we're at it, I intend to have my nurse live in and supervise the children.

LIFE at HOME: OUR WEEKENDS

Weekdays are scheduled right down to the half hour. Each minute I think, "What I'm doing is very distasteful and often painful but I can stand it until the half hour is over." Only then I start something equally distasteful, and so I exist by the half hour. So, I get pretty sick of other people taking care of me and my children after five days; no matter who it is or how good they are.

Saturday is the best day in the week. The nurse and housekeeper are not here and the family is alone together. Saturday starts much later than any other day in the week, because Vic sleeps late to catch up on the past five days of short nights. After waking him up several times during the night, I'm reluctant to wake him again in the morning, so I lie there and think of what to write later at the typewriter (Vic claims I think of mischief). I can think much faster than I can type, so what later comes out on paper is quite different from what goes through my head in the thinking hours. I'm also very stiff from lying in one position and using all my muscle power to keep from wetting. Sometimes my concentration is not quite good enough. Then it would have been better had I wakened him by the typical poke in his ribs with my weak left arm.

Weekdays, Mrs. Curtis is constantly with me during her working hours and keeps me groomed to the utmost. My hair is absolutely beautiful. My nails were long and polished, until I requested that they be cut for typing. My clothes are put on correctly and my runny nose is kept wiped.

Weekends are quite a contrast. When Vic gets up he dresses both of us in only a few minutes. He uses his strength and takes some shortcuts. He doesn't use the hydraulic lift to move me, because it takes more time than lifting me by hand and plopping me in position. Clothes are put on all crooked and uncomfortable, but after they have been on for a while they feel normal. My face isn't washed; that can wait for Monday. Quite often my hair doesn't get combed. It's full of hair spray and very difficult for Vic to handle. Children are warned to be quiet about this. It's no wonder my daughters go around all day without combing their hair. And yet this seems like the best day in the week. It's never routine and I'm not constantly watched. On Saturdays I feel almost as if the house is mine again.

But anything that's done on weekends gets raked over the coals on Monday. Of course, in the eyes of the help whatever gets changed is done "by Dr. van Lint who just doesn't understand anything about housekeeping." For example, one time we bought quite a few fancy doughnuts instead of going to a movie. I planned to freeze some and have them the following weekend. On Monday the housekeeper was instructed to freeze the doughnuts. But before she received any instructions, she ranted and raved about what she was going to do, and how it was such a shame to waste money that way, but poor Dr. van Lint just didn't know how to shop. This followed several similar incidents. I was very irritated, so I told her that I had made the purchase. The following weekend the doughnuts were not to be found and no one knew what happened to them.

I must confess that at first Sunday was a terrible day in the week for me. Vic read the Sunday paper and stayed with me while the children went to church school. Then one child stayed with me while the rest of the family went to church. I could very rarely hold on to the urine while Vic was gone, and he usually had a wet bed and a mad wife to contend with on his return. By this time everyone wanted some ugh!-lunch. During lunch they watched the various sports events, which are of no interest to me. Then the boys wanted to play ball and something always needed repairing. There was dinner to fix, dishes to wash, trash to put out, children to put into bed, snacks for parents and the day was over and time for bed again.

During the year the church changed the time that services and church school were held, and this no longer permitted driving time between the two services. Church services became a family affair. This rather forced me into attending the worship services and the adult discussions that followed. Sundays are now a beautiful mixture of the impossible, the nearly intolerable, and ridiculous, and also a chance to hear some intelligent speech, thought-provoking ideas, and facing of the facts.

Sunday starts out the same as every other day. I'm transferred into the hospital bed, panned and given my usual pint of water. Vic and the children get dressed for church and go out to the kitchen for breakfast. They like to fix poached eggs on English muffins. I am fed a bowl of poached eggs: thin runny yolks and squashed whites. At least that's my description of them. Somehow they don't seem to be my favorite, since thin liquids and tiny, rubbery pieces both tend to choke me. The liquid wants to run down the windpipe and the particles of egg tend to stick on the soft palate.

After such a delightful breakfast I'm again put on the pan. Only it's too soon and sometimes I'm a failure, or at least not a rousing success. In the meantime I'm trying to chew a doughnut. This sounds not too bad, except that I'm only able to chew with the front teeth. Everyone is in a hurry and then someone has stuffed a large bite into my mouth. This means that some of the doughnut is forced into the back of my mouth where my tongue has no control and can neither push the gummy mass forward or over to the molars. So there it sits - too big to swallow and unable to reach any teeth. But I feel as if I must keep trying to move this lump into a manageable position so I try sticking my tongue out.

By this time Vic and one of the children have started to dress me. The child may be an extremely silly girl, or a wisecracking boy, and I end up either screaming angrily or trying to contain the laughter. It's awfully hard on clean dresses to explode all over them. Exploding and spreading saliva all over the place is bad enough, but when it is mixed with half-chewed doughnut it's a disaster. In the meantime I'm still sticking out my tongue in a futile attempt to move the lump. My tongue is coated with a gooey substance that gets all over my face. Vic wipes it off and tells me to stop playing games.

My shoes are left off after the stockings are put on until I'm put in the wheelchair. As part of the process to get my dress down in back I'm told to stand up, while Vic holds on to me. This sounds very easy, but compared to standing with sturdy shoes, it's not. In fact it's almost slapstick comedy. The nylons turn out to be very slippery, a fact that ordinarily is of absolutely no concern. My feet go shooting out in front of me, while Vic is saying in a half annoyed voice, "Stiffen up and stop laughing," while trying to hold me up. I find it impossible to get my body weight over my legs. He gets discouraged and plops me down into the waiting wheelchair. The child holding the chair has his attention drawn away and forgets to push forward as I sit down. I end up sitting on the front half of the chair and lean way back. This position makes my head feel very heavy as it's hanging out in mid-air. At least I'm now sure that it's firmly attached.

We're going right out to the car, so naturally it's more efficient to move me as I am. I feel relieved when someone is behind me pushing the wheelchair. Then at least I have a headrest. Soon I'm transferred into the car and strapped in. I usually end up sitting on a slant, or what feels like a slant to me, even though everyone declares that I'm perfectly straight. My ankles are bent at an uncomfortable and unattractive angle. I feel straight all right: on a straight diagonal with all my weight on one hip. I indicate that I'm not right, but there is no time to straighten me out, so I'm left that way for the ride to church. By this time my dress is a mess of wrinkles, and a little girl leaning on me to help pull the straps tight only presses in the wrinkles that are already there. Once I looked forward to the day when I wouldn't always have a messy shoulder and a lapful of wrinkles from holding a baby. Now I make myself messy from coughing and the wrinkles seem unavoidable from handling me.

Next comes the transfer from the car to the wheelchair at church. I seem to go from one bad position to another. An attempt to straighten things out is made when we get off the parking lot and onto a level sidewalk. In the process my right foot usually goes into a spasm. To stop this my ankle is pushed back. Only in the backward push there is always an element of sideways push. On the footpiece of the wheelchair something hurts the foot when it is up against the side and starts a spasm so the foot doesn't know whether to stop or start its spasm. It finally stops

from sheer exhaustion.

I'm wheeled into place in church; Vic runs off to rehearse the choir and I start a right foot spasm all over again. Now the boys disappear to do their jobs in their classrooms, while Linda runs off to go to the restroom or to get bulletins. Karen is still young enough for childcare. Eventually the three older children come back. Although the boys don't actually make a lot of noise, they manage to be bossy and teasing, and they upset Linda. We are usually among the first few people there. After the children settle down, the people come and soon church starts.

I hardly ever look directly at the choir as they process in. I suppose this is completely wrong. People in the choir often ask me about the procession as well as the anthem. But so far I haven't been able to make myself watch a procession that I should be participating in. Even after being in church for nearly a year in a wheelchair, I still don't feel at ease when the familiar faces come in.

The service begins. I try to keep myself completely detached from what's happening. When an emotion gets started it doesn't turn off when I want it to. Sound, which is so difficult to make ordinarily, is part of any emotion and comes out when unwanted. Then I am angry with myself for not being able to turn off the sound at will. People have become accustomed to strange noises from me, but don't understand what prompts them. If I laugh at something funny, I can still be laughing with an uncontrollable sound when something serious is happening and vice versa. Most of the time I manage to stay detached and quiet by staring at one particular spot on a nearby heater.

If I do make some sound I mustn't look at the children, because that makes matters worse. They make all sorts of faces that say, "Oh Mother, be quiet, you're embarrassing us." Then I begin to wonder why our children have to be subjected to this experience, and things can go from bad to worse.

When the service is over, the children dash off to their various classes and Vic is usually busy contacting people for one thing or another. There's a short break while coffee and punch are served before the adults get together to discuss the sermon. By this time I'm wishing I hadn't had such a big drink of water, because nature is calling, and there's nothing to do but wait until I get home. Meanwhile, the ladies' restroom is an extremely busy place. Trying to keep your mind off this is not easy.

It becomes much easier when the discussion begins. In the meantime friends usually come around with lively conversation. People whom I've been fairly well acquainted with aren't embarrassed by my presence and act in their normal manner. People who have been passing acquaintances don't know what to do or say, and people who are strangers go to great pains to remain strangers. Little old ladies seem to have a special way of patting me and saying, "My, you are looking much better today, dear!"

When the discussion begins the time seems to go by very swiftly, despite my pressing problem, as all sorts of ideas and opinions are being tossed about. When the discussion period is over, I suddenly realize that my problem hasn't disappeared. It seems like an eternity before we

all get into the car, put the wheelchair into the car, drive home, go through the reverse process of getting me out of the car and into the wheelchair, up the two steps into the house, clear back into the bedroom, out of the chair, onto the bed and onto the hard, cold, stainless steel bedpan. Fortunately, I don't stay on it long enough for it to be too uncomfortable.

Then comes a part of the day that's relaxing to Vic but frustrating to me. I was never terribly fond of sports on T.V. but, of course, Vic is, and he's glued to the set. T.V. sports do only one thing for me and that is to provide greater motivation to get up out of bed and go fix lunch. But all I can manage to do is to grunt fiercely. That's the one thing that distracts Vic from the T.V., and he takes a rather dim view of missing all the good plays while I tell him I don't want him.

After some experiences along this line I try to shut out the loud sports announcer and think of the more pleasant time to come in a couple of hours. But after sitting through hockey, soccer, baseball, football, golf, bowling, and back to the hockey season again I'm becoming intolerant of Sunday afternoon sports. Meanwhile the children have changed their clothes and they're ready for a lot of activity after having to sit still all morning. Besides that, they're hungry. So they're usually wrestling in the house or rattle banging around the kitchen. This manages to keep my mind off the blaring sports announcer, all right. I'm dying a thousand deaths while four active monkeys are in the kitchen without supervision. Each one is fairly capable alone or in pairs, but put the four of them together on a Sunday afternoon and it produces mayhem.

When I am up, I see that my fears were not unfounded. The place is a shambles. They'll clean it up, but not until they are told to do so. In the meantime all the dishes are left exactly where they finished using them. Whatever was spilled is left until clean-up time. They've learned the hard way to put away food, but not well enough to find out what to do with anything unusual. If we happen to be going somewhere, they cover my eyes while Vic rushes me out the kitchen door. When they manage to clean up, I haven't decided which is more painful: watching the proceedings or having to criticize what they suppose is a clean kitchen. Is it better to accept the mess as a nice surprise or to try to teach them what "clean up" means?

Of course their idea of efficiency is to clean up while preparing the next meal. This not only produces a three-ring circus, but requires twice the normal amount of dishes. But they make up for it by using the absolute minimum. I suppose I worry too much about them attending dinner somewhere and asking the hostess what all the dishes are for and being amazed that a napkin is set at each place.

Sunday dinner is usually meant to be somewhat special, but at our house it means clean out the refrigerator. If we're not going anywhere there is always something to be done in or out of the house, or the children are always anxious to play with Daddy or play in the yard with friends. After the evening meal is prepared, eaten, and the cleanup completed it means to me that the peace and privacy of my abode will soon come to an end.

Why I prefer the chaos of a weekend over the cleanliness and orderliness of the weekday remains a mystery. And yet, in a way, I'm ready for Monday, which means a bath, clothes put

on neatly, and hair combed carefully

On weekends I get accustomed to being panned, dressed, put in the wheelchair, and combed in just a few minutes and I'm not forced to spend a lot of time in one spot. So there is time to go to different places or have people visit. Sometimes it takes all day Monday to become accustomed to the slower pace once again.

During the week I manage to be up about the time the children are due to arrive home from school. After they have showed me all their papers and have an afternoon snack it's nearly 4:00 o'clock. That seems like a strange time to be starting household chores, but that's what we do. Dinner is at 6:00 or 6:30 so we really have to make the time count. Laundry, dishes, cooking, making shopping lists, sorting cupboards, watering outdoor plants, cleaning children's rooms and various odd jobs are accomplished in this span of time. The children really have to keep going, and children have a tendency to drag their feet when they think they're not having fun. I'm the ogre who makes them stay with each job.

MY WORLD of EQUIPMENT

After I had been home from Rancho for a couple of months, we were notified that my own personal wheelchair had come in. I should return for a few days to have the wheelchair fitted to me and the equipment installed. All kinds of arrangements were possible, including me going back into the hospital for a week. This sounded horrible to me, but I had survived four months there without Vic so I thought I could stand a week with him there during the day. As it all turned out I stayed at my sister's house at night and spent two days at the hospital.

The two days were probably just a necessary evil to Vic, but to me it was quite a revelation to see only the efficient side of people. Besides trying to put their best foot forward, they were being gently but firmly pushed by Vic, whether he knew it or not, as he kept volunteering to be helpful and they had to keep up with his pace.

During these two days it was necessary to visit the orthotics shop once again and to do some waiting while the man who was working on my wheelchair went off into a back room to use a tool that couldn't be moved. Even this went much faster than in the past because Vic was mobile and could look into places that were inaccessible to me, and keep track of what was happening. So this last visit was a pleasure compared to the times when I had been left screaming from being in one position for much too long. This time I had along a person who could understand and appreciate the problem and do something about it nearly immediately. No more telling myself, "I can take the pain for another minute," and then when that minute passed telling myself the same thing over and over again until the small man who had instructions to "depress" me appeared and then still had to find unwilling help before my distress could be relieved.

I now have two wheelchairs. A lightweight one that is hand operated for travel weighs about 27 pounds, folds up flat, and can easily be put into a car. An electric one is powered by two 6-volt car batteries. **I**t was on this chair that most of the shop work had to be done. Its right-handed control is mounted on a piece of metal that swivels directly in front of me after I am in

the chair. This allows my left arm, assisted by the mobile arm support, to swing in towards the middle of the chair to operate the control, and also makes the cumbersome mobile arm support not quite so wide.

A lapboard was fashioned to fit the wheelchair with a hole for the control. Actually Vic used the power tools in the O.T. Department to make the lapboard, and here his accurate measurements came in very handy. It fits me and the chair perfectly. After a few days I discovered that I could operate the chair with the lapboard supporting my elbow and in fact had more control without using the mobile arm support. Thus, it became possible for me to go through average sized doorways.

The control device was mounted backwards as is done for people who have very little body control and poor balance. So when I pull back on the control the chair goes forward and vice versa. This means that Vic had to reverse the wires to the left and right controls. Getting used to the forward and backward control was not too difficult, but turning the control to the left and having the chair go to the right could be mighty confusing. After the orthotics shop fixed up the control on the chair and mounted brackets for trunk supports and brackets for the mobile arm support, I was sent back to the O.T. Department to have the mobile arm support adjusted.

Up to this time I had only been able to bend and straighten the elbow and move the arm to the left and right at a fixed height. The O.T. noticed that my mobile arm support was ordered with the capability for moving up and down. She was about to remove the feature, since she observed that I didn't use it on the borrowed mobile arm support. Vic said that he wanted me to try to use this capability, so some rubber band assists were put on. I still couldn't lift my arm. But having once embarked on this endeavor they were not about to give up. The O.T. kept adding more rubber bands and I kept trying to lift. Things looked pretty hopeless and then the crucial band was added and my arm went up very slowly. That was an exciting moment. The O.T. and I looked on in disbelief but Vic had that "I knew you could do it all the time" look.

The mobile arm support's range is limited but it was very thrilling to be able to reach my eyebrows again. I raised my arm up and down quite rapidly and was more excited than a child with bugged out eyes on Christmas morning. But disappointment came that same evening when my arm refused to move up and down. I soon learned that the time of day made a great difference in the amount of effort necessary to raise my arm, and that sometimes the effort was beyond my endurance. I also found it to be much easier to raise my arm while sitting up in bed, probably because the upright post on the bed with its hardware for mounting the mobile arm support is farther away from me than is the post on the wheelchair.

When I arrived home a few weeks sooner than originally expected, everything for my care had been ordered, but all of it hadn't arrived. The hydraulic lift to transfer me hadn't come, and we rented one so the nurse could handle me. When our lift arrived, the rented one was returned. Mrs. Curtis, who's fortunately half handyman, assembled the lift and started to get me out of my regular bed; then she discovered that this lift had larger wheels and wouldn't fit under the bed. Well, after putting me in the wheelchair all week with the rented equipment, she wasn't about to be outdone by the new lift. She was also good at improvising, so she went out to the scrap woodpile in back of the house and found a lot of pieces that had been cut off fence posts.

While she pried up the bed with a long board, the housekeeper slipped the square pieces of fence post under the legs of the bed. Meanwhile, I was receiving quite a thrilling ride. Anyway she raised the bed up enough to get the legs of the lift underneath and me out of the bed.

Those ugly blocks of wood stayed under the legs of the bed for many weeks. Then one weekend while we were shopping I saw some furniture casters and asked Vic if they would lift the bed up far enough. The answer was, "Yes, just barely." But we didn't reckon with my weight on the bed or the slight downward warp in the bed slats, so the lift fits only under the ends of the bed. If I'm on the bed, it's quite a struggle to get the lift underneath.

Soon after I arrived home more equipment started arriving. We soon found out that two sets of equipment had been ordered; one by the Purchasing Department of Vic's company and one by the hospital, even though the hospital had been instructed not to order anything. So everything had to be checked to see who ordered it. Some of the things had to be returned. For weeks after, whenever a truck pulled into the driveway, there was an air of expectancy not only to see what was coming, but who it was from. There was a look of "What do I do now?" on the faces of several truck drivers when delivery was refused. Things that were accepted were unpacked, assembled and put to immediate use by Mrs. Curtis.

In the mix-up of equipment several beds were delivered over a period of time. First, there was the bed that was ordered by the hospital, which was returned. Then came the bed that had been ordered by the Purchasing Department. This was used, but didn't operate as advertised, so the company that it came from agreed to take it back without the mattress. This was agreeable since we would need a mattress for the new bed. When the new bed arrived it was seven feet long, and we had a six-foot mattress. For many months that foot was filled up with square scraps of wood so that the mattress wouldn't slide when the head of the bed was raised. Eventually Vic fashioned a footboard that occupied the space.

Whoever invented the electrical hospital bed did me a great service. I could wear a nurse out in a very short time if she had to crank it rather than have me push a button while she's emptying a bedpan or carrying a tray. The number of times the bed is required to go up and down in the course of a normal day is not insignificant.

I liked this new bed, because I could operate the control. It could be handed to me because it could be removed from its holder and was on a long wire. The holder was attached to the right side of the bed. After I had this little bit of independence for a while, a problem developed inside the control box. The control had to be sent back to the factory. The one we got in exchange had a much harder touch so I couldn't operate it.

Many months later we had a physical therapist come in for a short time. She had a fit when she discovered that I had some grasp but the bed control was out of reach. So the next day I requested that the control box be moved. I tried it. Lo and behold, when I put every ounce of energy I could muster into squeezing, I could move some of the controls. I soon discovered that I could press each control if I had the box in the correct position. Getting it into position using only one hand was the biggest problem. Now that I was barely able to operate the control I wondered if I was getting slightly stronger or if the control was easier to operate since it had lost

its newness. I would like to believe my fingers were getting slightly stronger.

Of course, every once in a while the bed, for various reasons, won't work. I get stuck in one position when I need to be in some other position. If the bed sticks in a flat position it's possible to improvise, but when it sticks in the head-up position I am there for the duration, because no one seems to be able to operate the hand crank.

At an age of eleven, my son Kenny is already very interested in anything operated by electricity. Quite often he knows what the difficulty is and can fix it. At other times it takes more knowledge and experience. Any time all the electricity on the block goes off I'm really beyond help.

Another electrical gadget that's quite helpful sends water into my mouth at a slow controlled rate and I can let it drip into a basin. Since I have lost the ability to rinse my mouth out myself, this gadget can do it for me. It is quite an improvement over the old system, devised of necessity, where a large syringe (like a turkey baster) full of water was quickly squirted into my mouth. There was one useful, but uncomfortable, feature of this system. The sudden squirt of water made me cough up any loose phlegm and the next squirt of water washed it out of my mouth. It was quite an improvement over an even older system. My mouth was scrubbed with a wet toothbrush and not rinsed at all. That only stirred up stale tastes.

To sit comfortably for long lengths of time in the wheelchair, I have a small sized air pad that plugs into the circulating air pump, which in turn plugs into an electric wall outlet. This is wonderful when I have occasion to stay in one place. Unfortunately most people are used to the fact that I can maneuver on my own with the electric wheelchair, and walk off forgetting that I'm attached to the wall. If I happen to remember, I sit and wait until someone comes along. If I forget and start to move, everything is fine for a few feet and then, when the air hose is past its limit I feel that great letdown. When this happens, the hose usually becomes detached at the air pad. I'm sitting on the air pad and it's difficult to plug it in again. Vic is talking about getting the power from the batteries that run the chair, which would free me to go where I want to and still have the circulating air underneath me. This scheme would involve an inverter. If one as large as the one in the car is needed, I wonder if the chair would move with me, the inverter and the pump all sitting on it. I might still be sitting without being attached to an electrical outlet⁷.

Vic installed a buzzer so I could ring the housekeeper at night when he was out of town. At first, it was quite loud. I heard Iris tell Mrs. Curtis how much it scared her in her sleep, because it was directly above her head. She sounded quite exasperated but never complained directly to me, so I did nothing. The first time Vic was out of town, I remember ringing the buzzer three times. Iris claims she was out of bed five times. After that first night I tried quite hard to ring only once. I decided it was better to be miserable and quiet than to have everyone, myself included, completely frustrated. I had to ring once to be put on the bedpan and turned.

When Iris had been here several months, she asked Vic very sweetly if he could adjust the buzzer, which he did. By this time I had become quite accustomed to sleeping while

⁷ I lived with this problem until January 1975, when Vic found a small inverter that solved the problem.

miserable, and told myself that if I rang more often now she would become all excited and think something was terribly wrong, so I was stuck with trying to maintain the once-a-night schedule. One result of turning down the buzzer volume was that in the daytime it was very difficult to hear.

When Vic is out of town at night I sleep in the hospital bed with the buzzer available when I require help. In the summertime this works quite well, because I sleep with my movable arm out of the covers and can move it quite far away from the buzzer, but still find it quickly when it's needed. In the cold winter nights I'm much too cold to sleep this way, so the arm and the buzzer go into hiding for the season. This presents some unusual problems. The arm takes a very long time to move a very short distance with the weight of the covers holding it down. If I move my hand too far away from the buzzer I have a difficult time finding it again. If I keep my hand close to the buzzer I accidentally ring the thing in my sleep. Sometimes in my sleep the arm gets tangled up in the blankets and won't move at all. I wake up very sore and can't manage to budge the arm. At first I'm not too frantic, but try to call out. Only a very faint sound comes out. As I feel more and more helpless and hopeless, I become louder. Then my screaming eventually wakes up the housekeeper.

THE TYPEWRITER and I

When I first arrived home my only means of communication, besides trying to talk, was with a borrowed electric typewriter that had a manual carriage return. At first I couldn't operate it, but after trying for several days I could return the carriage a few times before my muscles tired out. It was set up on the kitchen table, so I could type only when I was in the wheelchair with the mobile arm support. It was a small typewriter and could also be placed on my plywood lapboard that fit onto the wheelchair. I typed very slowly. I wanted to say things that were meant for other eyes. I was made most uncomfortable by people waiting for me to finish, and having to edit everything I wrote.

I also disliked being given a limited time to type. I felt as if I were holding up the work of the nurse. She kept asking me if I was finished, and asking me to cut it short because there was work to do and she was only hired for an eight-hour day. But most of my typing time was used up in answering the housekeeper's questions. This was almost worse for me than the limited time available to me at Rancho. There I typed what was on my mind and didn't have to answer endless questions, and the O.T. assured me that she wouldn't read anything that I marked "Not to be read."

At home a lot of my typing was not understandable when I was through with it. I started a word; the person looking over my shoulder could talk much faster than I could type, and often guessed the word before I finished it. Then I went onto the next word without completing the first. The person might not guess the next word, etc. So I ended up with a conglomeration of letters and words that made no sense except to the person who had witnessed the typing.

Then there were hours and hours when I had nothing to do but watch television, practice speech, or try to move some muscle. My speech was very weak late in the day, even though I put a tremendous amount of effort into it. The other things got very boring and I wished that I

could use these long hours for something more productive. I felt useless. About the only thing I could produce was very slow typing. I begin to think how nice it would be if I could type in bed after the nurse left for the day. This would solve the problems of having others watch over my shoulder while I was working and read what wasn't intended for them.

While at Rancho, I was told that IBM sold reconditioned electric typewriters at a very good price to handicapped people who had a good reason for needing one. Vic investigated and found it to be true, but it was necessary to get on a list and wait for one to be available. So I expected a typewriter of my own, but didn't know when I would have it. It seemed too much trouble to tell the nurse that I wanted to type in bed, but she knew that I wanted to type after she left. Vic knew, too, and was thinking about the problems. The biggest question was how to attach the mobile arm support to the bed in the proper position. The nurse envisioned quite a fancy contraption to do this job, and planned to put the typewriter on the overbed table.

Then one day Vic walked in with the IBM. While he was there, enthusiasm was the keynote. After he left, the nurse began to examine the IBM more carefully. Then I heard, "This is too heavy for a woman to lift. It's too heavy for your lapboard and will break it. Where is the instruction booklet that should come with every new machine? Why don't you take this back and get a brand like mine? It's light and has an electric return and you could even turn it on and off yourself."

I didn't tell her that this machine was a gift from a church organization and that it was exactly like the one I had used at the rehabilitation hospital. We temporarily solved the problem of having to move the typewriter around by putting it on a table in the family room and leaving it there, and moving my wheelchair up to it to do any typing. The nurse still said, "That's fine for now, but how in the world will I ever get it onto the overbed table, which we need to use every day for many different purposes." I didn't know the answers to her thinking aloud, but was sure something would be worked out. It was much easier to listen to her worry than to quell her fears.

For a long time Vic and I had talked about writing of our experiences. One evening he inquired, "When are you planning to start writing?" I answered, "As soon as I can type without someone watching me." Soon thereafter he came up with a simple, workable design for a post to be attached to the hole in the side of the bed intended for an intravenous feeding stand. To this post is attached the hardware necessary for holding up the mobile arm support, which can now be used either on the bed or on the wheelchair. He also designed a table on casters to fit over the bed. The height of this table was chosen so that it could also be used with the wheelchair. Vic decided that he just didn't have the time to build the table himself, so he had it built. In a few days I had the wherewithal to type in bed and could start my writing. It also satisfied Mrs. Curtis, because she found that she could prop me up in bed with the typewriter.

When I first started writing I still couldn't read what I had typed on the paper. I could make out the keyboard and had to remember what letter I had just typed, whether or not I had spaced, whether or not the symbol or number I had used was in lower case on the typewriter, since it is faster to type in upper case when you only have the use of one hand), whether I had remembered to put on the shift lock after I used the lower case, all the while remembering the sentence I was trying to type. People say they understand how I developed a memory.

After getting no satisfaction from the eye doctor at Rancho, we decided I should be tested by an ophthalmologist at home. It took some time to obtain an appointment, but at last I had reading glasses and could read what I had typed. I had typed by only seeing the ~keyboard for so long that the change took a little getting used to. At first I caught myself trying to use my memory instead of my sight. The glasses still don't provide me the best vision. Jumping from one line to another remains a problem, even with double spaced pica type. Double vision can still occur after I wear the glasses for four or five hours. But I feel I must finish my train of thought, so I find myself closing the eye that will close by itself. This turns out to be the stronger eye and I finish with the weak eye.

Being unable to roll the platen back can be another problem. I may be typing merrily along on a certain subject when someone comes along and wants to talk to me. I can't change the paper so I space a few spaces and start talking by typewriter, indicating to the other to read. Most persons figure out where I've started talking to them and everything works out fine. Then they leave and I space a few more spaces and go on with what I was typing. This, too, is fine for that moment. Most of the people around me each day realize what I've done. Then sometime later individuals who are not around very much read what I've written and it doesn't make any sense. I want very badly to tell them to skip that portion, but they don't have a chance of understanding me, so it's better just to leave them confused and thinking I've flipped my lid.

Later, I decided that in the future I'd better cross out any conversation. This was easier to decide than to accomplish. I could spell out: "roll back." But the people around me were not familiar with a typewriter, so they'd roll up the paper because they couldn't imagine why I'd want to type over what I had finished. Finally they would get the idea, and I'd cross out the conversation and continue to type.

Then I hit the wrong key, and it happens to be the return key. So it's necessary to go through the same procedure again: calling someone and trying to make them understand that I need to have the typewriter platen turned back. When it's the busy time of day for the housekeeper and she usually has her hands gooey from cooking, I feel guilty ringing for her. Even if I ring for one of the boys with our buzzing code, Iris comes anyway, so I usually wait for someone to come down the hall.

Since I'm able to sit up only for a limited time, waiting for a child to appear can be very frustrating, especially when many ideas that I want to put on paper are running through my head. There sits the typewriter all ready to go, but on the wrong line. Often I just go ahead and type, leaving a big gap of paper but keeping the continuity intact.

Often adults who are unfamiliar with my ways will have something to say to me that demands an answer. If I can get my answer all on one line of typing, I'm in good shape, since I can back space and cross out the conversation. But if I come to the end of the line in the middle of a sentence I'm in trouble. I can cross out the uncompleted sentence and then go on to the next line, but then the persons for whom the conversation was intended do not understand why I've crossed out part of what I typed. They probably think that I've changed my mind, or that the operation did affect my thinking process despite what they've been told. Or I can complete my

conversation and try later to get someone to turn the typewriter platen back so I can cross out the conversation.

If people understand why I'm crossing out a line before pushing the return for the carriage, then they wait patiently and I don't have to try to get someone to roll back the platen later on. But I never know who will catch on and who will be thoroughly confused, so the only thing I can do is try everyone. Some people get confused, and become even more so when I try to retype the sentence I have just partially crossed out. "Just like a woman," they think. "She changes her mind and then changes it back to her original idea." It's difficult to explain the situation, and they go away convinced that my thinking has been severely affected.

COMMUNICATION: WAYS and MEANS

When we had the accident my youngest child, Karen, wasn't quite three years old. When I came home from the various hospitals it was the beginning of June the next year. She was to be four years old the end of September. I left a sweet little girl, and came home to a small-sized tiger. Not only is this an extremely critical time in a child's life, but it's a time when the child needs quite a bit of help. It's nice if it comes from Mother, who is usually more than willing to do whatever is necessary. Since Karen didn't read and I couldn't talk, communication between us was quite limited.

When I try to communicate by voice, I spell out some words, and try to say the words that are easier to understand. In their context they can usually be understood by a trained ear, but otherwise are unrecognizable. I have to spell the words that are difficult to say, so I create a lovely mixture of words and spelling. The great difficulty is that whoever I'm talking to has a difficult time telling the difference. Then add that some letters can be either a letter or a word, such *b* or *be*, and *c* or *see*. Then add the fact that we quite often write in abbreviations, but I have to spell everything out or create havoc.

Fortunately, I had arranged for Karen to attend pre-school a year early. Thus at least three times a week she spent the morning with an adult who knew children, and she had some contact with her peers. I don't know what the housekeeper did for her, but I do know she spent a good deal of time with shoelaces flying, clothes on backwards, unbuttoned and often inside out. Everyone considered her to be a very quiet little girl. She wasn't really, it was just that each time she spoke there were many voices louder than hers, and it wasn't until she was five years old that she began to assert herself.

During the many months that I wasn't home she learned survival via blackmail. It seemed to work well for her when she used it on older brothers and sister, so she had no reason to expect that it wouldn't work on other people. She was at the point where if she didn't get her way she kicked, screamed, bit, hit, or any combination thereof. So when I came home and we got a new staff she tried it on everyone. It worked fairly well with the housekeeper, who was supposed to be responsible for her. Whenever she and I were alone she threatened me if I said "No" to her wishes. So I said, "No." By this time I had learned to take pain quite well. But she got more than she bargained for when she tried these tactics with Mrs. Curtis, who simply picked her up, spanked her upper legs, put her in her room until she quieted down and then went to talk

to her. She had met her match at last.

Karen still took afternoon naps. She wouldn't let anyone but the nurse put her to bed. I had asked Iris many times to spank her, but she couldn't bring herself to the task and always rationalized it away. Then my little girl got very vicious one day, and I insisted that Iris had to learn to punish her if she was to be responsible for her well-being. So the housekeeper did what she had to, and the little girl cried for quite a while. The housekeeper cried for a while too. The next day Karen requested that Iris put her to bed. I had to remind the housekeeper that the events just possibly might be correlated. After that Iris was not so timid with her punishment, even though some of it did take the rather unfortunate form of screaming, and Karen let the housekeeper put her to bed. Eventually, they made a game out of the ritual. Karen would hide and Iris had to find her before she would go. It came to be quite a happy occasion.

As I write this, Karen is over five years old and brothers and sister are getting very, very tired of being threatened by little sister. They're ignoring her wishes and are still strong enough to withstand her attempts to retaliate. Now she is going through the "Nobody likes me" stage, but she still tries threats, along with physical torture on older brothers and sister. The other children had learned that was not a good idea long before they were five years old. I wonder, is she slower in learning this because she is the baby of the family, or because she hasn't been helped or corrected enough?

I can make her stop fighting the other children, but making her understand why it's wrong is another matter. The person in charge of the children does what she can, but it still can be extremely frustrating to watch someone else do the job that you want to be doing. Another person never handles the situation quite the way you would and you are convinced that your way would be more effective with your child.

It does become extremely frustrating when you see your children trying to learn how to do something that you would ordinarily help them to learn. They are turned down by the person from whom they ask help, or are taught in a manner that you feel is not correct. Things that the boys are interested in aren't quite so bad, because they ordinarily ask their Dad these questions. But when I hear the girls asking questions about sewing, knitting, cooking and girl-type subjects I certainly have the motivation to try to do something.

When I try talking to a youngster who can't yet spell, I have a real problem on my hands, especially when I'm supposed to make the decisions and am unable to explain them. The child, of course, wants a "yes" answer to his request. But I can see a danger ahead if I give a blanket "yes" and am forced to say "no." So the child often hears "no" from Mother. Soon I find myself looking for things to say "yes" to. People around me might be affected by my answer, though it seems unimportant at first glance, and I have to stop to see how it might affect others. The child takes silence as consent, and then proclaims "Mama said I could." So I end up having to make lots of people unhappy when I had the best of intentions.

Or there are many people in the room all engaged in conversation with one another. In this room is my small child, who is bored by the whole affair and thinks, "As long as so many people are talking, I don't see any reason why I shouldn't." The child asks me a question while

I'm listening to another conversation. I move my head to see or hear something and the child takes this as the answer "yes," which he was looking for. Then I'm in real trouble. There are too many people around and everything becomes confusion, including a child who insists I said he could do whatever it is that he's doing. Meanwhile, I don't think I've said a thing. Now I'm afraid to move at all for fear of being misinterpreted.

One problem is that I didn't realize how fast people are able to talk until I just tried to nod my head "yes" or "no" before the speaker was off onto the next question or statement. I usually find myself left in the dust answering something that's way in the past as far as other people are concerned. But they believe that I'm with them, so I might irrevocably give an answer to one question when they believe it to be in response to a completely different question. Also, although a question is not always clearly, truthfully answered yes or no, people have only a short time to spend and demand a simple answer. For instance, they say, "Is this dress too long? Just answer yes or no." If I could talk I would quickly say, "Yes, but the whole dress is too big." In this case if I answer "Yes," the other person is soon off shortening the dress I prefer to have left alone.

Mrs. Curtis and others loved to tease me about the strange answers that I gave to their questions. What happens actually is this: my mind and that of the other person are clicking on two different subjects. The other person, having no difficulty with speech, introduces a topic, usually in the form of a question. I quickly answer and forget to check whether the other person catches my answer. Then, having at last obtained attention, I quickly go on to the subject on my mind. Thus, I thoroughly confuse the other person, because I'm hard enough to understand without talking about an unexpected subject.

Mrs. Curtis, my efficient and understanding nurse had one habit that's annoying to me. She constantly showered me with double questions that required opposite answers. For instance, "Would you like to have pears, or would you rather have peaches?" By the time I answer the first question the second is over already. Then I attempt to answer the second question, and it looks as if I'm answering not only the second question but changing my mind. After a while I decided to ignore the first half of a double question and always answer only the second part. This didn't make the questioner aware of the double question, but at least I'm not quite as frustrated by being misunderstood and constantly teased about my indecision.

Mrs. Curtis had another annoying habit common to a good percent of the people I've encountered. They imply, "You have nothing to do, so use your memory and remind me to do such and such." So I pick what I think is an appropriate item to remind them of. Then they act irritated and say, "I haven't forgotten, I simply haven't had the time yet. Give me a chance." After this happens several times I say, yes, I'll remind them, but don't intend to do it. But, if what the person has asked me to remind them about seems important, it's difficult to forget. So I'm not consistent.

The subject of what is important is a touchy one. What's very important to me is frequently a subject for ridicule to another person. Normal people can usually take care of what's important to them, but I'm usually forced to laugh it off.

One of the things that annoyed me greatly while I was in Scripps Hospital was going into elaborate detail to spell out what was hurting me, all the while attempting to keep from screaming. The red headed nurse would finally discover what was wrong, try to correct it, and ask, "Is that better?" If I said, "Yes" she was satisfied, even though conditions could still be improved. If I said, "No" she told me she couldn't do anything for me. I don't believe I ever heard her ask, "Is that all I can do?"

It was frustrating to have Vic start out able to understand me better than anyone else, and then have other people learn his method and be able to carry it out much faster than he can because they get more practice. Why frustrating? I suppose it's because for such a long time he was the only one who could understand what I was saying. Now he is one of the last to catch on, but I still expect him to be better than others.

It seems as if I should be able to invent some kind of a sign to indicate when I have heard someone guess what I'm trying to say. Very often some adult is trying to translate and there are a bunch of children trying to be helpful, but all talking at the same time, when one of them hits the right idea. To me these words seem to stand out, but they're just part of the background noise to the person who is trying to concentrate on what I'm saying. It's extremely frustrating to have to sit and listen while children are taught correct manners of not interrupting, when one of them has just come out with the idea I'm attempting to put across. Then when I do become understood by the translator, I feel as if I'm refuting what the children have been taught.

I should be able to invent another signal which means I'm changing the subject. Usually people will have something on their minds, and come and ask me a question that I can dispose of quickly with a shake of the head. At least in my mind the subject is closed. I go on to ask a question that has been burning in my mind. Only other people believe I'm answering them in more detail and are still thinking in terms of their subject. So they can't make any sense of what I'm trying to say. I have no other way of getting their attention, and they are always busy thinking about what has to be done for me next, so there isn't much time left for conversation. Sometimes I need the information from the question I'm asking before I can give an answer to the original question. Often in this case the subjects still seem unrelated. Thus I have gained a reputation for not only answering a question with a question, but for changing the subject while I'm about it.

I think I have described how things happening at a normal pace are much faster than I can manage. Thinking in this vein, you might imagine that someone says something that doesn't demand an answer as far as he or she is concerned, but a retort to it immediately comes to my mind. In this situation I find myself fighting with my mind to keep **my** unintelligible sentence from just coming out. Often I lose the fight after a struggle, even though I know that the other person won't understand me anyway. The other person gets halfway down the hall and then hears a whole string of noises from me. Usually by the time he or she gets back I'm sorry that I lost the battle, since now I can't get a sound to come out and certainly not all the words of the intended retort. And in any case the retort should be made quickly to be effective.

FOOD and PERSONAL CARE at HOME

Iris was a fairly good cook for plain foods, and a real believer in having a variety of vegetables. Unfortunately, there are several vegetables I don't care for. The children know about some vegetables that I really dislike, but Iris teased and said, "How do you expect me to get your children to eat different vegetables, when you won't?"

I wanted to tell her, "Just don't serve turnips, cauliflower, broccoli, and Brussels sprouts," but she wouldn't have heard me even if I could talk normally. She was convinced that she was teaching the children to like all sorts of new things. They were required to clean up their plates to get dessert. So they told Iris they liked the dinner, and then came to me and described graphically how terrible the vegetables tasted.

One time Iris thought she could pull a fast one on me. She served me turnips ground up to resemble mashed potatoes. One bite and I pulled the worst face you've ever seen. At that point she stopped trying to teach an old dog new tricks. But she never gave up on the young ones.

Mrs. Curtis was convinced that honey was good for the muscles and used it in place of sugar. Suddenly she decided that she wasn't getting enough honey into me. Without telling me she started putting honey into my orange juice each morning. It tasted different than just plain orange juice, but was palatable. But when the taste changed, I began to cough and choke on the orange juice. Apparently something about the combination made it very difficult for me to swallow. The nurse was thoroughly disappointed. She just had to get some honey down me somehow and wondered next if I could eat it plain. So I tried that and spluttered even more than when it was hidden in the juice. Oatmeal was one of the things the nurse used honey in. It happens that oatmeal was enough to gag me even before I had surgery. But the nurse talked me into having oatmeal for breakfast. It's her belief that if I would eat oatmeal I wouldn't need the suppositories to stimulate my bowels. I gagged on oatmeal for nearly a year and the suppositories were still necessary.

Once I could stand food very hot or extremely cold. Now, either one produces a violent reaction. If I get anything that would feel warm to the average person, it seems hot to me. If I accidentally am given something that's nice and hot to the average person, it burns me and out it comes. When I taste something cold I have a dramatic facial reaction that looks like it is sour, until my mouth is acclimated to the cold temperature. I eat ice cream for its liquid content and because it's one of the few smooth things that I can take without choking, gagging or coughing, though the cold temperature is disagreeable. By the time the end of the day comes I'm in no mood to cope with anything difficult for me to swallow, such as a thin liquid. Everyone teases me and tells me I don't need an excuse to like ice cream.

I'm unable to drink from a cup and I soon flatten a paper straw, so I have to drink through a plastic straw. A hospital nurse once tried me out on a glass tube. My jaws unintentionally clamped down and scared us both half to death until she managed somehow to get the broken glass out of my mouth. It's a strange phenomenon that while my lips refuse to seal tightly enough to keep from dribbling liquids, and don't have the pressure required to make certain sounds, my teeth refuse to stay apart enough to keep from ruining a paper straw. It took a lot of effort and a great deal of time to learn to suck through any kind of a straw, and when I do so my

cheeks suck in along with the liquid. This can be quite a problem when the teeth insist on chomping down on my sucked in cheeks. I can't manage to chew my food but I do a good job biting the inside of my mouth. I continually had a sore mouth as the various nurses insisted on getting a certain amount of liquid down me each day. I wanted to have my thirst quenched after having felt parched for many months, but every time I sucked in I was rewarded by pain.

Puffing out my cheeks is something I have been trying to achieve since the very early days of the paralysis and I have just recently been able to puff them out a very small amount. And keeping my cheeks out beyond my teeth while drinking liquid is still in the future.

Mrs. Curtis started me drinking coffee again. When I first started to take food and drink by mouth again, I discovered that coffee now tastes very bitter to me. It was a long time before I would admit to myself that it would be good with sugar.

I need to have my solid food ground up, but must beware of grainy foods, such as ham or hamburger. Pea shells, even mashed, can give me a lot of trouble. I'm ready to give up and eat something more comfortable, but Vic keeps insisting, "You must learn to eat these things again."

If I start choking during a meal it seems to continually get worse. When I can manage to avoid coughing during the beginning of the meal I can sometimes condition my throat to accept grainy foods. Sometimes, too, I'm lucky when they're cooked in a creamy sauce. But if I've started coughing, even that doesn't make the way smooth enough.

It's easier for me to swallow liquids when I'm in a lying down position, for then the liquids easily pass over the windpipe and go into my throat. It's difficult enough for me to drink from a straw in the normal position. Often I need a drink when I'm on the double bed, which doesn't rise. As the container can't be tipped, I end up trying to suck and swallow with the straw sticking out of the corner of my mouth at 90 degrees from the normal angle. My lips are already quite leaky and with the straw in the corner of my mouth parallel to my teeth it's a wonder that any liquid at all gets swallowed. Recently we stopped in a restaurant that had plastic flexible straws. Now we know they are available; all we need to do is to find some and they should keep everyone happier. Meanwhile, we also have a plastic cup with a cover and a straw hole for babies, complete with Mickey Mouse. It can be propped up next to my head, so Vic doesn't have to hold it for me anymore.

Eating seems to produce coughing and coughing seems to bring up phlegm. When the nurse is here she knows what it means when I open my mouth and try to stick out my tongue after a coughing spell. She usually gets a Kleenex and wipes off my tongue while I try extra hard to keep my mouth open, but pull my head away from her fingers if I feel a spasm coming.

When Vic is here and the phlegm comes out, he thinks it's the same as coughing and holds a towel up in front of my mouth to protect whatever is within range. Meanwhile, I have my mouth wide open and I'm trying to stick out my tongue and wipe it on the towel. The only way that I have to do so is by vigorously moving my head back and forth. So it looks like I am sticking my tongue out in dislike for the towel and emphatically indicating that I don't want the towel. It looks as if I'm violently rejecting what Vic thinks is help. So he puts the towel back on

my chest and out of reach of my tongue. By this time I have closed my mouth, but still have the distasteful stuff in there and I'm forced to swallow it with the next bite of food. Is it any wonder that eating is not my favorite occupation?

My nose has a habit of running generously during a meal. This can be real fun. The family thinks it's hopeless to wipe my mouth until I'm finished with the meal. But when it starts to run the mucus heads right for my mouth. Now I can't open my mouth and I won't be wiped until the meal is finished. It seems like the thing to do is to point to my nose, but my hand has a spoon clamped into it and I've already scooped up some food. I try pointing anyway, and my son tells me to stop trying to feed my cheek. So there are only two things left to do. Both end in disaster. I either refuse to open my mouth, or I open it to yell and get a mouthful of mucus.

Vic often works late in the evening and the children feed me dinner. A part of dinner is two pills. I'm accustomed to swallowing these pills with my ground-up food. Anything that goes to the back of my throat is past my control and slips down my throat. This could be a convenient help in getting down the pills, and I've told the children to put the pill on the tip of the spoon. They do it that way one time, remarking on how fussy I am. The next time they feed me, the pill again goes on the spoon behind the food and off to one side.

That's the one place where the food has a chance of reaching my teeth. And I'm supposed to practice chewing! I eat only a small amount of food and these two pills use up a good portion of it. I should try to chew, but I have run into a pill all too often, so I try to get these bites back away from the teeth. This leaves very little food to practice on, and that doesn't really make me unhappy, since I cough my way through dinner anyway.

At lunchtime I feed myself with the aid of the mobile arm support. You might think that on a do-it-yourself project I could get the size bites that are appropriate to what I'm trying to accomplish. Not true in this case. I seem to have very little control over how much food I get on the swivel spoon that's strapped to my left hand. This particular spoon is slightly larger than an ordinary teaspoon and is round, like some soup spoons. I suppose it was designed to be an all-purpose spoon. It's the junior size in this model. I can imagine the performance I would put on with the regular size spoon.

I can usually manage to stop the scooping action soon enough to let the excess food fall off the spoon, but when I do get a large amount I'm really stuck. The arm brace and mobile arm support don't allow for turning the arm (what the therapists call supination) and anyway the swivel spoon is designed to always stay level. By raising my arm up as far as the mobile arm support will allow and dropping the arm at the elbow, I can try to shake some food off but it sticks like glue. My arm just won't move fast enough to do any good.

The only way to get the food off the spoon is to eat it. It looks as if I'm a real glutton, since I have to open my mouth as far as possible and try to get all of the food in, or some of it will stick to the handle. I could try to make it in two bites, but that usually ends up in more disaster than I am about to create. So I end up by putting the tip way back in my throat, which irritates the soft palate and produces a coughing spell.

At lunchtime I don't have the problem of the inevitable pill possibly coming into contact with my teeth, because the nurse pops it into my mouth just ahead of a glass of tomato juice. The juice goes down very quickly, because I can manage a thick liquid by this time, even sitting up very straight.

When I was in Rancho there was a choice of either coffee or milk to go with the meals. I hadn't started to drink coffee again and milk is distasteful to me, but chocolate milk is palatable. Refrigerated chocolate syrup was available but not handy to the many different people who fed me, so syrupy chocolate was eliminated from choice. This left the powdery variety, which could be kept by my bed. Granular chocolate milk tasted much better than chalky, cowy, plain white milk. So for four months I had all possible varieties of lumpy chocolate milk. When I came home the powdery stuff came with me. Mrs. Curtis just naturally assumed that the powdery variety was what I preferred. There were too many other things to straighten out to worry about this subject. Anyway the nurse always made syrup out of the powder before adding the milk. Thus I graduated to having granular chocolate milk only on weekends. This went on for many months.

Finally we somehow got on the subject and I mentioned that I preferred chocolate syrup. To me the change was also a timesaver. Sticking the can in hot water to make it pour easily seemed to be very little trouble. Everything went along very smoothly until the first time Vic tried to make chocolate milk by pouring directly from the refrigerated can.

But I had choked down enough of the granular stuff, so the syrup remains. Everything is fine as long as the can is first opened and is at room temperature. But if it comes from the refrigerator it tastes like cowy, slightly colored, just plain milk. I was greatly relieved to find that this was apparent to my smallest daughter. How do I know? One time she was drinking what she thought was chocolate milk and said in a very plaintive voice. "This tastes just like plain milk."

Iris is black and has a terrific sense of humor. When I drink, I still sometimes cough and explode unexpectedly, without enough warning to turn my head in another direction. Every time I have an explosion while drinking chocolate milk and splatter her, Iris tells me she wishes I would drink something she can see to wipe off.

At dinnertime I avoid any liquid, because it goes through me very quickly and I'm in a poor situation for anyone to get the bedpan under me that fast.

Dinnertime is supposed to be at 6:30 p.m. when Vic is in town and a littler earlier when he's out of town. A little earlier means about 6:00 p.m. to me. This caused more difficulties than you might imagine. Our children have to walk a half mile to school and it's uphill all the way back. So I told them that they could have something to eat when they got home from school. Unknown to me, Iris was planning their dinner for about 5:00 p.m. and once fed them as early as 4:30 p.m. She got very upset when they ate anything at all after school. So there I was, between hungry children and a very sensitive housekeeper. Hungry children can be quite appealing and insistent, so I let them have a piece of fruit. This put me in Dutch with the housekeeper.

I have always disliked group picnics; because it always seemed the men folks escaped to play organized games and the women were left to change diapers and chase toddlers. The irony of my situation is that now that my children are old enough not to need watching every minute, I'm still with the people who have to watch babies.

If I don't go out in public with my family, they can't go places that a family should go. I certainly want my family to have as many advantages as possible. If I refuse to go out in public, at least one of them will have to stay at home with me. So we all go everywhere. It's not easy to feel as if all eyes are staring in my direction (whether they are or not), but it's the only way to maintain a somewhat normal atmosphere. So there I am, whether I like it or not. I'll probably always feel a twinge of the 'everyone is looking' attitude, but I've become accustomed to this emotion and can usually ignore it.

I seem to spend a lot of my life dealing with a bedpan. I used to be more modest than average. Now my personal needs involve not only the nurse, housekeeper, husband and children, but sometimes arise when we're out in public with friends, members of our church, service station attendants, etc.

I never look forward to being put on the bedpan by Iris. Her technique is different than any other used on me. It stretches some muscles that haven't had any therapy. It's very painful, but I'd better be quiet or I'll never get on the pan when I really need it. Her technique seems like a lot of work. Most people bend one knee, and then they roll me onto my side and slip the bedpan underneath. Mrs. Curtis bends both of my knees and lifts up my legs to slip the bedpan under me. She puts pillows on edge to keep my knees bent, and then raises the head of the bed. This technique is quite involved, but it does serve to exercise my legs and puts me in a position that's close to normal. Iris lifts one hip at a time and sort of scoots the bedpan under me. Then she lifts one leg at a time, and puts a pillow under to pad the bedpan, and then leaves me flat. Thus, it seems that the bottom half of me is raised up while the top half is flat. But usually I'm so happy finally to be where wetting is safe that I urinate anyway. When she wants to get me off the filled bedpan she has quite a problem. Quite often she spills a little and puts a towel over the spot. If Vic is out of town, and I've spent the night in the hospital bed; the nurse may find the towel the next morning after breakfast. She has a fit; because my skin has been against terry cloth all night.

A menstrual period can be a bad time in a woman's life, but in my case it seems that everything that happens is attributed to it. Now take the other day. I have some pills for cramps. They are very effective; but quite difficult to swallow and very nasty if you happen to get a taste. I got the pills down all right but their taste insisted on coming up. Normally I expect to have this happen, but the bad taste is a lesser evil than the cramps. This time when the bad taste appeared it made me want to swallow, but when I swallowed it felt as though I had a knife blade in my throat. So I had my son give me a bite of peanut butter, in the hope that this would take care of the taste and I could avoid swallowing. Unfortunately, the combination of tastes was extremely bitter and I seemed to swallow even more often. About dinnertime this was still bothering me so I decided to try a bite of jelly. My son thought I said Jello. I decided that would be good enough. Only he thought I wanted a whole dishful, and kept stuffing it in. This only served to

get him in trouble, because all the children were supposed to be helping prepare dinner. The voices of all five people seemed to be sounding at once. It seemed as if I could hear each conversation very clearly, but could have absolutely no effect on what was happening, even though I was involved in each explanation that was being offered. All this because I took pills to help one problem and created more. Maybe it would have been better to suffer through the original problem.

I have a very heavy flow about the second day of my menstrual period and wear two large pads on this day. This hasn't bothered me previously, but one Sunday they must have been placed incorrectly and they were pinching me. I had the feeling that if I could spread my legs apart everything would be fine. But every time I tried to spread my legs apart they seemed to push together, making the pinching worse. I tried to concentrate on each word coming from the pulpit and get my mind off the problem, but the pain only seemed to increase. I thought I'd never make it quietly through the service, but the minister was kind to me and kept the service short. When the clamor of voices started I could hold out no longer in silence and began to cry. Of course, everyone thought I was sick and tried to comfort me. Vic came quickly down from the choir loft and tried to help. I decided right then and there that I was going home. Just being moved would solve the problem and I could regain my composure without staring eyes.

There was a situation in the family room which bothered me greatly. A tray, a couple of plate guards, a special spoon, a big plastic bib, some plastic straws, a rubber mat and various other items that were used for me were kept out in the open on the dining room table. Mrs. Curtis had a fit if anyone laid a sweater, or a newspaper, etc., on top of these items. Iris was forever complaining about the lack of storage space. I thought about how I could solve all these problems and make everyone happy. So, while Vic was doing some construction work out in the garage I had him build some shelves over the washing machine.

The nurse read everything I wrote, so I knew she would find my note addressed to her and the housekeeper. I wanted her to read it to Iris and put the proper interpretation on the note, in case Iris might find something in the note that would hurt her feelings. In the note I asked the nurse and housekeeper to move the cleaning supplies to the garage, which cleared a wide cupboard above the broom closet and allowed the housekeeper to put away the cooking utensils she didn't use, besides making a little space for the things that were kept on the table.

I thought this would make everyone happy, including the family and me. I have heard that it's impossible to make everyone happy, but now I found out by experience. I was quite surprised to learn that I had made Iris extremely bubbly, and Mrs. Curtis dissatisfied. Mrs. Curtis seemed to be resigned to the fact that I didn't like having these things kept out in the open and made quite an issue of teasing me about it. For some unknown reason she wanted to put the nursing supplies instead of cooking utensils in the high cupboard. I refused, because I'd been thinking about all these problems for some time and this would bollix up my plan.

What probably gave me the courage to refuse was that we were looking for a replacement for the nurse, so I told her that I was afraid the next person wouldn't be able to reach that high. As things have turned out, this was a very valid reason.

I managed to have my way for the first time that year.

It had taken almost a year to get used to the fact that this is my house and not a hospital, where nurses often have to be firm with the patients. Having the nurse and housekeeper choose to wear their white uniforms makes the atmosphere that of a hospital and not a home. I believe this adds to my attitude of, "You must do what you're told," and in this way try to keep peace.

FIVE YEARS LATER

Five years have passed since I came home. Three children are teenagers; only Karen is still in elementary school. There has been very little improvement in my muscular control. I still type with one finger, and control the joystick on the electric wheelchair. My speech is still very weak. Only my family and a few friends can understand me by listening to the sounds I make and reading my lips. About half the time they catch one word at a time. Otherwise I have to spell it out.

My experiences have been broadened. I've endured and enjoyed a number of housekeepers and nurses. I've been to restaurants, plays, and movies. I've been on vacation trips by auto, airplane, train, and motor home. I've watched the children grow and have had a hand in their upbringing. I've cried and laughed, felt hurt and delight, been frustrated and overcome frustration. There have been risks. I've fallen out of the wheelchair, I've been tipped over with the wheelchair, I almost drove the wheelchair into our new swimming pool, and I've felt petrified with fear during many trips up and down stairs. Probably the most ambitious adventure was a five-week vacation in Europe with Vic. At first Vic was worried about complications should I catch cold. I've had colds and recovered. All in all, I wouldn't consider trading my experiences for a safe, protected life cooped up at home.

About a year after I came home, it was necessary for us to look for another nurse because our insurance payments were soon to end. The insurance paid 80% of the cost of a registered nurse, but nothing for a practical nurse. When the insurance payments ended we could no longer afford the salary that an R.N. commanded. Our idea was to have a practical nurse live in and be in charge of the children under my direction. The children would be brought into much closer contact with me, but it meant changing both the nurse and the housekeeper. I was very excited about this idea, since I had come to understand how important it was that the housekeeper has good vision and is not terribly sensitive.

Still, the right practical nurse had to be found before we could even begin to look for a different housekeeper. The right one proved to be very hard to find. She had to love children, be able to discipline them, learn the hard nursing work, and be available to live in during the week. Four or five tried out for the position during several months of looking, but none got past the nursing part of the job.

Finally we had an interviewee who seemed to be good with children. Pat had many years of experience in practical nursing, so I decided to give her a try. She seemed to be very slow, but much more interested in learning the job than the other candidates. We were like Mutt and Jeff, since I am tall and Pat was very short and extremely heavy set. I was worried that she wouldn't

be able to handle the leg exercises. It did seem to be a problem, but she tried very hard and thought she could improve with time. She worked a week with Mrs. Curtis and then we were on our own. There was a great deal to learn in one week, and some of the things mentioned she didn't absorb. I remember being frustrated one time when she asked me a question and I attempted to answer. I was quite patient, while she ran around in what looked like an aimless fashion searching for pencil and paper. I was still quite patient as she spelled out and wrote down the answer. But I then discovered that after all her work to understand my answer, she had forgotten the question. I found out later that it was necessary for her to write everything down, because she was a poor speller, but could recognize a word half way through if she wrote it down. She was quite quick to pick up the individual letters but they didn't seem to form a word in her mind.

Now that we had found someone to fill the live-in-nursing and child-supervision position, it was time to find someone to do the housework. We were extremely fortunate to have the first person who applied for the job, Lillian, work out very well. She cleaned up dirt that no one else tackled. Each week everything was cleaned in place. Every month all the furniture was moved and every nook and cranny was thoroughly cleaned. The bathrooms got a real scrubbing; they hadn't been that clean for some time. Iris had cleaned up a lot of mold that had accumulated during the time I was in the various hospitals, but Lillian made everything sparkle. She cleaned even where the dirt didn't show and this seemed to make the parts that did show appear more sanitary.

Wintertime, even in mild San Diego, is an uncomfortable time of the year for me. I'm given a shower on a small enclosed patio. Even with a small electric heater there, it can get pretty cold. I'm put on a tilt board covered with a bath blanket, strapped down and tilted into a standing position. Then I perform some facial exercises and am tilted back into a horizontal position for the shower. Things feel fairly comfortable up to this point. The shower is given by uncovering only half of my body at a time. A dry bath blanket is put on me before taking me back inside. The wet sling is still underneath me for the return trip to the bed. Despite all these preparations and precautions, things get pretty cold during this process. Even Pat, who is in her bathing suit, gets wet and cold. And she can move around. I try to keep my mind off the temperature. When that fails I try to remember how well off I am compared to people who die of exposure to bad weather over long periods of time. This seems to work fairly well until the housekeeper remarks on the temperature and starts wondering how I can stand to be wet in such weather. Pat says, "Now I understand why people in the old days didn't bathe all winter."

I was still very nervous with Pat. When she first came she was repeatedly forgetting to spread apart the feet supporting the lift. Doing so makes it more stable and I feel more secure. Several times I felt the lift falling and cried out. Then she spread the feet of the contraption and I seemed to straighten up. One time I yelled, she spread the feet, but I kept on falling. Luckily, we were near the bed. She quickly put me down on it and then examined the lift. A bolt had fallen off. I was confined to bed for the balance of the day. The bolt couldn't be found, but in Vic's pack-rat collection he found one that fit. He happened to be in town that day so he fixed it that night, and I was able to use the lift the following day. I suppose I was spoiled by having this sort of thing be noticed and repaired by Mrs. Curtis.

I grew used to the fact that the straps holding up the sling were often twisted. Pat didn't notice them and couldn't understand why I was so crooked. I soon learned that she appreciated having this sort of thing pointed out to her, even if she discovered it at the same time that I did. All the others had wanted to discover these things for themselves, or at least learn from someone who could tell them quickly.

Another time I made it out to our enclosed patio and outdoor shower after having a tipping fright at the door, where the feet have to be narrowed to get through. I had my shower and was on the way back inside the house when I noticed why something felt strange. The lift was not putting me into a sitting position because the left strap was on the right side and vice versa. Pat didn't discover my plight until she had struggled to put the front wheels of the lift over the doorway. While she struggled, I felt myself slip, and could envision myself landing on the concrete patio. There we were, in the middle of the doorway. Pat, who was more panicky than I, asked if she should put me down outside. If I were going to fall, I preferred to fall on the carpeted hardwood floor instead of concrete, so I indicated "Proceed." We made what seemed to me a very long trek to the bed with me in a flat position and my head hanging over the sling. It brought back memories of being lifted at Rancho.

Pat usually ended by calling the housekeeper for help, so she concluded that for her peace of mind and mine she would have Lillian help as a regular thing. I've stopped worrying about tipping over with the tall, strong Lillian behind me.

About the time it was necessary for us to change to a practical nurse, Vic started to build a tilt table. It was finished and put out on our little bedroom patio. When we tried to use it with the lift we discovered that the feet of the lift wouldn't fit underneath. While we were waiting for it to be rebuilt we went back to using a lounge chair for my shower. The tilt table was pushed aside. Somehow in the moving it got turned around so that the feet were closest to the shower handles. When Vic went out to rebuild it; it was left just as it was. It was rebuilt so that the lift will only fit under one side. Now, when it was tilted and I was in a standing position I had, instead of a view of the trees in the yard, a beautiful view of a wall and two bathroom windows. When it was used as a table for the shower Pat squeezed herself around the table to wash my face and hair. I used the table in a horizontal position for the shower after I had been standing while doing bulbar and tongue exercises. When I was in a vertical position there was plenty of room to walk around me, but when I was down in a horizontal position there was no extra space.

After typing this I discover that Vic built it facing the wall for privacy, but since I was always covered when standing up the reason loses its validity. A beautiful example of a good reason, but without communication on the subject it came to exactly the wrong conclusion. It happens to me all the time. Since the lack of communication is on my side of the fence, you can guess which solution is implemented. Frustrating—yes, it is!

One day I was sitting in my bedroom in the wheelchair when I heard a noise that sounded as if the housekeeper had opened the bathtub faucet in the other bathroom. The water had the sound of great force. I was a little surprised, but thought she wouldn't turn it on too hard so I wasn't terribly worried. Suddenly I noticed water spurting out from under the sink in my bathroom. What a helpless feeling! I was the only one at home who knew where the main water valve was located, but I couldn't tell anyone fast enough to do any good, and the people who

were home were much too excited to find out anything from me. The nurse finally got Vic on the phone at his office and the water got turned off while Vic was still on the line. Meanwhile, everyone, including me, had forgotten that I was due to have visitors, so no one listened for the door. Amidst all the confusion, three women, who were strangers to the nurse and the housekeeper, came in through the bedroom patio. When the fountain subsided and left a thoroughly wet bathroom and a partially wet bedroom, one of the threesome pitched right in and mopped up and then introduced herself.

For months and months I kept asking both the nurse and Vic if there wasn't an ingrowing eyelash by the outside corner of my left eye. Vic looked and told me I was imagining things, since he didn't see anything there. The nurse had a method of pulling the top eyelid over the bottom eyelid. Then she asked me if the eyelash still bothered me. I answered truthfully, "No," but couldn't tell her that now my eyelid hurt so much that it camouflaged the other trouble. What probably happened was that my tears lubricated the eyelash and it didn't bother me again until the next morning after having my eyes closed during the night. Then one Sunday afternoon we had friends visiting us and the eyelash began to scratch my eye. I asked a woman friend to look in my eye. At first she saw nothing. Then on closer scrutiny she discovered in the outside corner of my left eye an attached eyelash that was growing under the eyelid. She used tweezers and pulled it out. Right away my eye felt better than it had for months.

I've always had a problem with dandruff. The four months that I didn't get a shampoo didn't help the situation at all. Several of the nurses in the hospitals were quite concerned about this matter and tried many different solutions. Mrs. Curtis worked on the same problem. I endured very hard scratchings several times a week with a fine comb, and different preparations rubbed vigorously into my scalp. I once believed I had a tough scalp, but I began to believe I was quite a big sissy. Once a week my hair was washed with a special shampoo that had been prescribed while I was in Scripps. Mrs. Curtis also set my hair very close to the scalp. Here again I believed I was getting soft, since it pulled to the point of silent tears. When it was dry and combed out, it looked beautiful. Once more I really knew what is meant when it's said that women endure great pain in order to have beauty.

My hair came in slightly wavy after it was cut in the hospital to accommodate the traction device. When my hair is kept cut short it doesn't need to be set. This also seems very fortunate, since Pat didn't know how to set hair.

When I first came home from Rancho I decided that I'd better have a very simple hairstyle so that Vic and the children could comb it on weekends. I didn't care for myself with a center part, so I had Mrs. Curtis comb and cut it with a side part and comb it back with one pin up fairly high. I overestimated the abilities of the others in my family. When it did get combed on weekends they couldn't seem to manage a straight part and either put the pin too high or way too low. It came out pompadour style. So I figured, if they insist on combing it that way I might just as well have it cut and set that way. The only trouble was that it insisted on falling into a center part. During the week Mrs. Curtis could keep it beautifully combed and under control with hair spray. The hair spray made it hard for Vic to comb on the weekend, so I ended up with a rat's nest with a natural center part.

I told Mrs. Curtis of my dilemma and asked for her suggestion, but she simply couldn't understand why anyone couldn't comb through the old hair spray and apply new. So for a long time I ended with the same problem, plus the fact that my hair kept blowing in my face and I couldn't brush it away. The hair tickling sent me into spasms with my right leg sticking out. Anyone who saw it would try to bend my leg back into a sitting position. But the hair continued to make my face itch, making the leg difficult to bend and making me uncomfortable.

Then one day my speech therapist arrived with an exotic but simple looking haircut. It had bangs and a center part, was cut short, and looked very attractive. "Aha," I thought "this will solve all my problems." So I asked Mrs. Curtis to cut my hair like the therapist's. She did a beautiful job of cutting it and it did solve my problems. But I came out looking very much like my small daughter, or a picture I had seen of my mother, taken before I was born, of which I had later disapproved. But I still have a variation of this hairstyle, it doesn't need hair spray, it doesn't blow in my face, it doesn't require setting, it's simple to comb, and it doesn't require re-parting over the weekend.

Since the girls have no one to help them with their hair on weekends I was compelled to find a style they could manage by themselves. It turned out to be the familiar style calling for a center part, straight bangs and cut short. This is the hairstyle that I'd vowed my children wouldn't have to endure. I had this style as a child and thoroughly disliked it. I refused to go all the way and had their hair cut straight around and not shingled up the back. Linda has naturally wavy hair, so it looks acceptable on her. Karen is still too young to be conscious of vanity.

Then the girls decided they wanted to have long hair. Since I like long hair on little girls, I couldn't disagree. So we decided to let the hair grow but keep the bangs and the center part. This looks messier but does give them some chance to learn to do other things with their hair. The girls both have natural side parts. When their hair is parted in the middle it tends to make an 'S' curve at the crown. It takes very careful parting when the hair is wet to avoid this problem. Most of the time they go around with a gorgeous 'S' curve. On weekends the hair just randomly goes to whichever side, it wants to. Linda can part her hair, but when she does it's usually on a diagonal. I became extremely irritated about this subject on Sundays when we attend church, but I've finally just tried not to look at the uncombed hair when we are late and Vic doesn't have time to check hair. So both girls have what I wanted, but have to wear their hair in a style which I thought would never happen.

Both girls think if they are told to comb their hair we must be going somewhere. Pat explained to them that they should keep it neat and make it easy to comb, but on weekends they revert to their natural tendencies. They also don't fathom why they should comb their hair if we're going someplace where it will get all messed up anyway. But I suppose that's asking for a lot of understanding when even their father doesn't understand it enough to explain it to them.

One of the most frustrating experiences I've had was trying to teach Linda how to braid her hair. I slowly spelled out instructions, but she couldn't understand, no matter how simple I tried to make the directions. Finally Larry said he knew how to braid and proceeded to show her. That was when he found out that braiding hair is more difficult than braiding leather. In the end both boys and the girl helped to achieve a very loosely braided tangle. Each child held one

strand of hair and passed it on at the appropriate time. Linda wore her hair that way for the rest of the day, but fortunately she soon decided she wanted to have her hair cut.

One time I remarked to Pat about how fast the years of training a child could break down, particularly their table manners. It was one of the days when Vic was out of town, and she mentioned something about feeding them at the snack bar that evening. Suddenly a danger signal appeared in me. I asked her what she meant. Iris had told her that whenever Vic was out of town the children were fed at the snack bar. Then she asked, "Isn't that correct?" I replied, "No" and started to laugh, while she looked panic-stricken. She felt terrible because she hadn't checked it with me, and I felt like an idiot because they had been eating there for a year, or maybe more (who knows what happened when I was in the hospital), without my knowledge.

This was a period of time when Vic was out of town as much as he was at home. I didn't ever get up for dinner when Vic wasn't home. So the children hadn't forgotten all of my training, they had just been taught bad table manners. That very minute Pat went out to the kitchen and reported the misunderstanding to Lillian, and she quickly reset the dinner places. She was happy about the change, because she disliked feeding the children their dinner at a snack bar.

About the end of December one year our housekeeper Lillian, had to leave. We found that replacing her was not as simple as it appeared. In the months that followed we had many different people and sometimes had no one for a week at a time. But somehow we had to have a meal in the evening and clean clothes for people to wear. Pat knew very little about cooking, but was willing to do what she could. I planned very simple menus and tried to tell her how to prepare them. When I said something like "sauté onions," she not only didn't know what it meant but had to stop to write down anything over a three-letter word. Quite often her hands were wet or messy from cooking. So she had to stop to clean and dry her hands before writing down a word that wasn't understood anyway. Then I tried to find a short way to describe what I meant, seeing the non-comprehension on her face. Thus it took two people a much longer time to prepare a meal than it should have. But we did get through this tedious ordeal and kept the hungry faces happy.

The children had little experience with a washing machine. What they had forgotten we taught them. Anything that didn't require ironing could be worn. We went about a week without a housekeeper. Then someone applied for the position, worked long enough to catch up on the ironing, and quit. But at least cooking dinner got much easier after two or three weeks of experience.

We finally decided we were doing well enough without a housekeeper, but we needed regular help for ironing, mending, and cleaning. We thought this would be the equivalent of about two days a week. Finding someone to fill these requirements proved to be much easier than trying to find a full time housekeeper. The budget was much happier about the situation, too. Pat found she could do many things without help.

I got used to being handled again by one person; the main difference was that Pat used the children as helpers rather than try to keep them away from me. She started by using them as

helpers in some portions of the nursing care. After she became more acquainted with the kitchen, she found them to be pretty much at home there. There are times when the nurse has to be away and the children, under my direction, can prepare a meal of several different fairly simple things. They are acquainted with cleaning up the kitchen, so this is not a problem. Fortunately we have an automatic dishwasher and they've become proficient at operating it. Our last full-time housekeeper quit about the beginning of May. With the summer coming on we decided to try the new system and manage until school was over. Summer came and went and everyone became used to having to do their share. The following fall our favorite housekeeper, Lillian, returned on a part-time basis. She always does more than is expected of her. When school started we found that the children were rushed, but with the return of the hard working housekeeper we could manage fairly well with her help three days each week.

I use each child's natural behavior patterns to my own advantage. Larry is the type that can make order out of a jumble of belongings in a short amount of time. Kenny has an uncanny sense of knowing just what I want done without taking all the time for me to say what I need. Linda has more patience for detail. Karen is too young to spell and can't understand my words even if she guesses the letters, but is eager to help when another child translates for her. It would be nice to try to teach each child the other children's good points, but sometimes I don't have the patience for this and I'm happy to know that it's possible to use each child's strong points. If the right person is busy, it's sometimes less frustrating to wait until he's free than to try to get the wrong child to understand and do what seems to come naturally to another one.

At first I decided that it wouldn't be very good training for the children if I disagreed with the nurse when she told them to do something, thinking she knew my interpretation of a given situation and believing she was passing on my words. So I didn't ever reverse any directions. Then I found that more and more I was really losing all hope of my opinions and wishes ever finding their way down to the children. I had all too little control of what they were being taught. Besides, it was extremely frustrating to me (whether I was correct or not) to be trying to impart one opinion, and before anyone understood it, hear the opposite direction forcefully given, as if it were mine. So I started acting as if I didn't even hear the nurse, and went on talking to the children.

I can now actually see some of the fingers on my right hand move ever so slightly. Others claimed they could see them move years ago. When the footrests are removed from the wheelchair and there is no friction against my feet, I can, with great effort, raise one or both of my legs a few inches. My tongue can now move toward the left far enough to reach the first molar.

I remember being elated when my right hand moved into a tight fist (even though it was not commanded to do so) rather than being absolutely limp and motionless. Now I find it to be a mixed blessing, because I'm not yet capable of straightening out the fingers. It makes a strange kind of fist where the thumb gets caught underneath the fingers and the thumbnail digs into the palm of my hand. But that's a small pain and I've long ago learned to not let the little pains cause me any concern.

My right arm is usually placed upon my body. If it's left by my side it refuses to bend

when the head of the bed is raised and gets a squeeze play which hurts proportionally to the amount the head of the bed goes up. It's also placed upon my body so that when I'm rolled over my 150 pounds don't land on my arm. In the very early days after surgery, and before communication was possible, this was a big problem for me. Invariably my arms landed underneath my body, especially if the sheets were just being changed, or I was having my back washed and was only turned over for a few minutes. I was very relieved when I learned to move the lower half of my left arm out of the way myself. It made the turns to the left much more comfortable. But then I dreaded the turns to the right even more. Eventually I was able to make them understand my almost unintelligible cry of, "My arm, my arm," but it was many months before that was possible.

There are problems that occur, too, when my arms are up on my body. In order to get clothes on me, it's necessary to bend me far forward at the hips. My hands always seem to gravitate to the joint between the upper leg and the hips and get caught in the middle when I am leaned forward. There my fist gets squeezed by my own body. This makes the thumbnail push even harder into the palm of my hand. Meanwhile, the process of leaning me forward gives a good stretch to some muscles in my back and legs and I really feel it at the back of my knees. Sometimes the pillows are not placed quite properly, or I am leaning too far to one side and I get to go through the whole process again in the space of a few minutes. I have to remember how much better this feels than in the days when I had no control over my left hand and both hands got caught in similar situations. What a wonderful thing it was to finally be able to move one hand out of the way of whatever befalls. And how frustrating it can still be when almost anything gets in the way and prevents my left arm from reaching its destination.

I've heard somewhere that you aren't supposed to categorize people, but that's exactly what I intend to do. When people are dealing with me quite a lot they just naturally fall into categories. I don't mean visitors. They are another story. I'm talking about people who live with me or work with me. I may have a problem with which I need help; quite often some part of my body is caught in a painful position. People of one type don't care what the problem is, but just want me to tell them what to do and start doing it quickly. This is a good system if these persons have understood correctly, but quite often they misunderstand and either make the situation worse or create a second problem. People of the second type want to know what's wrong and proceed to figure out their own solution. They are usually not in a hurry, and take time to find out if they understand the problem. Unfortunately, they're in no hurry with the solution either. Then there are the ones who wish to know the problem and my solution and then proceed with their own solution. This third type is usually not slow, but wastes a good deal of time finding out my solution. Through it all, I'm expected to stay calm so I can be understood and remember which type of person I'm dealing with. People recognize only the type of person they are, so, "Of course this is the only way."

The contrast between the weekends and weekdays is still something to behold. Each has its merits and frustrations, but I believe it's hardest to get used to the weekday frustrations. Or maybe they just seem to last longer. They take longer and try my patience more. On weekdays things seem to be done very carefully while I hold on in scared misery, and on weekends things happen very quickly, but I'm likely to have a toe scraped under the footboard. On the weekends I'm dressed very quickly, but it's frustrating to have everything messy. On the weekdays I'm

dressed very neatly and comfortably but am frustrated because it takes so long.

MOTOR-HOME VACATIONING

By the time I was home for a year we were feeling pretty confident of the family's ability to handle me. We regularly went shopping together and to restaurants, to the San Diego Zoo, to visit my sister, etc. I was being lifted in and out of the front seat of the car on a heavy sheet. Vic lifted on one side of me and held up my back, needing an adult or a couple of children to lift on the other side.

A little over a year after I came home the whole family took off on a four-week vacation in a rented 26-foot motor home. We traveled with the generator on, providing electricity for the small circulating air mattress which normally stayed in the electric wheelchair. I sat upon this on a couch along the side of the bus. There I could lean against the wall of a small bathroom at the back of the couch, have my legs stretched out on the couch, and see out a picture window alongside. The driver's seat was at the forward end of this couch. Sometimes I sat with my back to the back of the couch, leaned against the driver's seat, and looked out the window on the opposite side of the bus. When I got very sore I tried (not always successfully) to stand it until the next stop and then lie down and be turned on my side, using the back of the couch to prop me.

Meals were anything that could be found already prepared and canned. Canned dinners, canned or fresh fruit, and canned fruit juices made up the main part of the menu for dinner. Breakfast was cereal, eggs or pancakes. Lunches, which could be fixed while we were traveling if we were on a fairly smooth road, were sandwiches and fruit. Vic and the three oldest children became proficient with a can opener and the children managed to do quite well as the clean-up crew.

Laundry was done once a week and was really quite something. All the bedding was stripped, which is a funny thing to see in a small space. The bedding, pajamas, and towels were added to an already huge collection of laundry. To this was added any clothing that was hanging in the little bathroom because of my accidents. Everything was sorted inside the bus into piles that could be washed together. One heap was made on each of the dinette seats, one on each table, one in the hole formed by the steps into the bus, and one on the couch beside me. Of course the floor was used for several more heaps. Some of the piles would get mixed together and I watched, hoping that things got sorted out again inside the Laundromat. Vic and the children ran between the bus and the Laundromat with their unwrapped loads of clothing, dropping things along the way and picking them up on the return trip. On a washday we practically took over the whole Laundromat. Somehow, amidst the panic, things did come back clean and not nearly as rumpled as they went in. We took nothing with us that had to be ironed, and nothing got ironed. It was a real wash-and-wear affair.

We found most of the Laundromats to be quite standardized in cost and method of operation, but did come on one little place, just over the Canadian border, in a very small town near an Indian reservation, that was taking the poor to the cleaners. The manager was indignant when Vic tried to put signs on the machines that were inoperable. Without the signs you could

keep putting quarters in different machines until you found one that worked. The place had its washers set so that they didn't spin too much water out of the clothes, and this way the dryers needed to be fed more money. It was the only Laundromat in town; therefore people without transportation had to patronize it. Vic, who hates to write letters of complaint, looked without success to see if the place was part of a chain of laundries, or who owned it if it was a local business. The information was not easily available, written or voiced.

Getting me in or out of the bus became quite a fine science before the month was over. It took two people to accomplish this task. When leaving the bus, Vic carried me in a bear hug from behind while one of the boys carried my feet to keep them from dragging. They set me on the step of the bus. Then while the boy steadied me Vic climbed around me. After he got in front of me, he pulled me into a standing position with a bear hug and then swiveled me around and lowered me into the waiting wheelchair. Getting me back into the bus was the reverse operation.

Previously I had trouble keeping my stretch Capri's pulled up high enough. Now I was having just the opposite problem. My stretch pants were a convenient handle. Each time I was carried they went up a little bit higher. When I was plopped down in the wheelchair the crotch of the pants cut deeply and felt very uncomfortable. After a while I learned to have a child pull down on the legs of the pants. This didn't always solve the problem. Sometimes the child pulled hard enough to get the legs down where they belonged but not hard enough to free the crotch. Then the stretch pants would act like a rubber band and spring back up by the time I was placed in the chair. My dual-purpose plan had failed and to lift me up again was too hard on everyone. Fortunately, there was enough scenery to see so that my mind would not focus on the tight crotch.

We spent a lot of the time in that month in various National Parks in the U.S. and Canada. Naturally, Vic and the four children wanted to take hikes. The first time they went for about an hour I was left lying on my side on the couch with a note on the window in case of an emergency. My bottom felt fine but my legs felt as if they were being weighted down by heavy logs. Both legs hurt but the leg that was on the bottom of the pile was really getting the worst of the deal. I ended up trying to stop screaming, but the more I tried to stop the louder I got. On the way back from the hike, Larry ran ahead of the others to check on me. He moved my legs, so that by the time the rest of the family arrived I was somewhat calmed down.

The next time they left for a hike they tried carrying me back to the bed, turning on the generator, hooking up the big air mattress and leaving me on my back but propped up so I could see out of a window. This worked fine for a couple of times. Then came the day I slid sideways on the prop pillows and ended up against a partition that formed a wall for the kitchen area. While they were gone for two hours, I slid down about halfway through. It wasn't too bad except that my ear was turned under and trying to move my head made matters worse. For once, I wasn't afraid of falling. I was wedged in too tight! After that Vic padded the partition and things worked smoothly.

One great adventure for me was being carried aboard a cabin cruiser for a tour of a lake. I expected to be left in the bus on this occasion, but Vic insisted on taking me along. At one

point during the trip there was a short hike planned for the tourists. Vic stayed on the boat with me and the elderly. One of the tourists played mother to the four children and watched over them on the hike. She said it felt natural, because she had four grown children of her own.

Our bus was completely carpeted, except for the bathroom. This was wonderful with four children and a man doing all the kitchen work. The rug got shampooed of necessity one time after we were parked on a slight slope that made the bus tilt slightly toward one side. The generator was on, causing some vibration. A pan full of lasagna fell off the stove three times before Vic discovered that it wasn't falling because the children bumped it. We had a lovely lasagna-colored rug and it didn't want to become turquoise again.

Towards the end of the trip we discovered that I could ride in the front seat, up by the driver, if I was tied in place. Riding up front with the engine beside me and the road directly below was an eerie feeling by itself, and when I was tied to the chair it became a most insecure feeling. I had to have complete trust in the driver for at times I felt as if I was hanging over the side of the road.

We did some night driving and since the couch doubled as a bed for the boys, I had the choice of riding in the back of the bus on the bed (which made me car-sick) or traveling up front tied to the chair. In back I was also 26 feet away from the driver. Although my conversation was not very scintillating, I'm a very good listener and felt that with Vic talking there was a better chance of him not to doze off.

Vic usually drove until he got sleepy, and then found a place to stop for the night, untied me and carried me with my feet dragging to the bed in back of the bus. The dinette made into a bed which was used by the two girls. It was very close to the couch flattened into a bed for the boys. Just walking through this narrow space was hazardous, and trying to get through while dragging me was heroic. Anyone witnessing this maneuver would probably have doubled up with laughter, for we must have resembled an old time slapstick comedy. When we got back to the bed, Vic had to sit down and I plopped in his lap. This looked hilarious, but it was uncomfortable. The next step was for him to get me off his lap and onto the bed and then hold me up in a sitting position with one hand, while reaching for my nightclothes with the other. It was all possible because everything was so compact. The two of us could sit side by side on the long part of the bed and take up all the available room. The rest of the space was occupied on one side by the side of the dresser drawers, and on the other by the side of the kitchen cabinets.

At last I was laid on a bed with an air mattress. The mattress had already been pumped up and now it was time to pinch off the air hose and turn off the noisy generator. This also stopped the pump which circulated air through the mattress. Thus, I was effectively back to the hand-operated air mattress. But I slept very well on it, usually waking up to be turned only once during the night.

Each morning was quite a production. Children rolled up sleeping bags and dumped them on the other side of my bed (over the top of me), pulled clothes out of the jammed drawers, dressed and tossed their nightclothes near their sleeping bags, made breakfast and cleaned up afterwards. Somehow during all the confusion I was fed, dressed and moved. Then we were

ready to drive. Riding in the bus was wonderful, because the children could be active while we were driving. When we stopped somewhere, and I was in the wheelchair outside the bus, Linda who was seven years old, wanted to do arm exercises on me. Only she could not remember what to do. It took me a lot of time to spell it all out. Some of the words she didn't know and had to run and ask someone what they meant. The next day arrived and she couldn't remember what to do and wanted me to spell everything out again. After several days I finally understood she was not really interested in doing the exercises, but felt very important when she could translate what I was saying. It did wonders for her spelling even though my arms didn't always get their exercise.

Vic and the children could go on and on using what they needed and never putting anything away, letting things fall to the floor and leaving them there until they were needed again. I took all this disorder (efficiency in their eyes) as long as I could, which couldn't have been too long, because my tolerance for disorder is not great, and then made my wishes known. It didn't seem to help any with everyday tidiness, but every once in a while they realized that a grand cleanup was needed.

I got a shower once a week in the small bathroom inside the bus. The whole room must have been about as big as our stall shower at home. It contained a sink about the size of a cereal bowl, a chemical toilet and a hose with a spray attachment that was the shower. Vic had quite a challenge in getting us both through the small door at the same time. Once we were in this small room he sat me down on the toilet seat, leaned me up against the wall and proceeded to wash and rinse both of us. He could dry himself and most of me and then try to get this half-wet thing into a standing position, out the small door and onto the bed, which had been spread with towels. The whole process took a good forty-five minutes. When Vic finally got out of the shower room he was as wet with perspiration as if he hadn't bothered to dry at all.

My hair required shampooing each week to keep the itching from driving me and everyone else insane. We found it convenient to place me on a chaise lounge (garden variety) out of doors and have children carry pans of water from the bus, which were poured on my head and drained through the webbing on the lounge chair. Washing my hair in this manner instead of using the small bathroom in the bus was much more satisfactory for all concerned. I was supported full length and far more comfortable than sitting on the porcelain and leaning against a wall. Vic also had both hands free for the job at hand. The children were called upon to be messengers in both cases. My hair was washed in this manner from San Diego to the Canadian Rockies and back again, usually at campsites, but we've also been known to pull up alongside the road and do the job beside the bus.

We lived in this manner from San Diego, California through Montana, seven parks in the Canadian Rockies, Vancouver, Seattle, San Francisco and back down the coast and home again: 5,000 miles of canned dinners, searching for laundries, filling up the water tank, dumping the used water tank, rolling and unrolling sleeping bags and seeing spectacular scenery.

While we were on the trip, I necessarily had to lie on my right side quite frequently, because the topography of the couch on the left side of the bus naturally headed me in this direction. So it was convenient to put me on my dreaded right side. This allowed the left arm to

rest on my body. Thus it was already up off of the couch.

I thought, “It’s hopeless, but I’ll try again to get my elbow and the upper half of my arm up in the air.” I tried over and over again and at last it went up off the surface of my body ever so slightly. I was exhausted from this experience, and felt as if I had lifted something that was much too heavy for me.

I was also very exhilarated and felt I had to do it again right away or this ability might be lost forever. So I tried over and over again and each time I could lift my arm slightly higher. I did this a short time for several days in a row. I found I had a little more endurance if I said, “Up, up, up,” as I tried to lift. I finally got my arm almost to the halfway point and put all my strength and energy into lifting.

Suddenly I got past the halfway point, and although it was still hard, lifting became much easier and my arm went straight up until it hit the wall behind me. At home I had practiced holding my arm straight up in the air after the nurse had leaned it against a lamp attached to the left side of the head of my hospital bed. So when I got my arm up in the air I could hold it there or move it around as long as I didn’t go below the halfway point. It was great fun.

To think that after two years I could at last move my whole arm around on my own power. There was a curtain just above me and I found I could brush it and even hold it aside. My arm could even serve a useful purpose!

I could arrange to see out of the window without having to attract someone’s attention and try to make them understand. Then I realized that just holding it in the air or moving it around in this position was great fun but too easy. I had to practice putting my arm down in a controlled fashion, not just let it fall, and then practice lifting it again. Each time it was very difficult to lift up to the halfway point, but once I got past that it was comparatively easy.

Even the first half became much easier after much practice. It was difficult to make myself lower my arm past the halfway point, because I was never sure that I could get it up again. When the muscle became too tired I didn’t have the strength to get it over the hump. Then I was frustrated and lost control of my emotions. It was terrible to have had that arm in the air and not be able to put it up there again.

I thought to myself, “I’ll never be able to practice this at home because I’m either on my back or on my left side.” When I got home I tried it on the hospital bed on my back. I found that having my arm up on my body had been a great advantage. I still can’t lift it straight up, but if I employ some of what a former nurse calls ‘the side lift’ I can get it up to the lamp above me. It still takes all the lift I can manage to get it up when the arm is in the proper position and there is absolutely no friction. The side rail on the hospital bed has to be down or I don’t get enough ‘side lift’ to do me any good. Another thing that I found is that I have to be perfectly flat to accomplish this great feat.

If the head of the bed is raised even the slightest bit it becomes impossible for me to raise my whole arm at all. But I keep trying. Who knows what will happen in the future?

Despite the many inconveniences this was one vacation that I was sorry to see come to an end. Besides seeing many different and exciting things, for the first time in two years I didn't have to face the fact that very soon I would be under the care of an employee. I didn't get my face washed, teeth brushed, hair combed, bath, and clean clothes, each day but I did have nearly a month of not having to listen to another woman play with the discipline of my children while, to all appearances, I looked stoically on the scene. The children, mainly the boys, did some tall griping about the discipline they received from their father. But now they only talk about the good times they had and don't seem to remember all the griping they did about how they expected the vacation to be fun and how restricted they were. I suppose that's part of boyhood, but it's pretty hard to listen to without stating my opinion. On the other hand, had I been able to state my opinion, it probably wouldn't have been my privilege to hear such private boyhood chatter.

But the four weeks did have an end. Vic went back to work, the children returned to home-cooked meals and friends to whom they could boast, and I returned to the daily therapy.

AIRPLANE TRAVEL

The following spring, Vic and I decided to try traveling as just the two of us. We planned a three-day stay in Las Vegas, during which we would be on our own without being able to call on our little helpers. Packing, even for a short trip, was complicated. We had to remember all the odd items; air mattress, pump, pills, suppositories, bedpan, straws, etc., required for my daily life.

We had decided to try flying. The various airlines make special provisions for their wheelchair customers. I don't believe they counted on anyone completely helpless, however. We did see to it that I wouldn't need a bathroom during the short flight—large diapers!

The first step was to take a taxi to the airport. For two tall people to get into the back seat of a taxi at the same time is a real feat. We did manage it, but for a while I wondered. The taxi driver looked a little strange when Vic asked him to lift on the sheet under me, but he helped. Vic had to back into the narrow back seat with me following on the lifting sheet, making sure I was leaning back enough to avoid hitting my head. We squeezed into the cramped quarters and I was dumped onto the seat. After Vic made sure that I was balanced, he had to get back out, fold up the chair, and load it into the trunk of the cab. The look on the driver's face seemed to say, "I thought I had seen everything." Even the trunks in taxis seem to be small, and the bags had to be loaded into the front seat. The ride seemed like a short respite.

The airport came within sight and soon we were pulling up to the loading zone. Vic unpacked and unfolded the chair. Again I was lifted out and into the chair where I landed with my legs straight out and difficult to bend. Vic struggled with the legs while the meter ticked on. Finally, my legs were bent and put under the foot straps. Meanwhile, the driver dumped our bags on the sidewalk.

Fortunately, there are usually porters eagerly awaiting someone really in need. A porter

delivered the bags to a ticket line. For a short spell Vic got to take care of both the luggage and me. The luggage was weighed, ticketed, and sent on its way. Then the agent discovered that the chair was to go aboard also, so I got a baggage ticket too.

Then we made our way to the waiting area by the gate. There we were informed that I must board the plane via a special wheelchair. One more transfer than we had counted on! After a short wait they notified us that they would like me to board before the others. We were taken to the foot of the stairs where the special wheelchair was waiting. It's a most peculiar looking thing. It looks long enough for the likes of me but it's very narrow and without sides.

I was transferred before I had time to think about what was happening. It was a strange sensation; almost like sitting on nothing. At this point, I was supported on each side by the men who began strapping me in like a refrigerator on a dolly. I discovered the strange sensation came from hanging over on both sides, not only on the seat, but all the way up. The men carried me and 'The Thing' up the fairly narrow staircase, which was barely wide enough for all the people who were trying to help. Vic was right there, too, helping and trying to assure my safe delivery.

We purposely had tickets for the first seats. Vic had grabbed the air pillow out of my travel chair and now put it in the seat near the aisle, in which he planned to plant me. Putting me by the window was virtually impossible. We went through the usual bear-hug transfer and there I was, in the seat of a plane while Vic went down to make sure my chair was put aboard. I had a chance to calm my jangled nerves. He came back before the long line of passengers streamed by.

The flight was an ordinary one by normal standards, but everything about it seemed special to me. I certainly never expected to be a passenger. Not being able to turn or duck my head to see was a bit frustrating. Even though I had become accustomed to not doing these things, the old impulses were very strong. It was rather a shock when my body wouldn't respond.

First on, but last coming off. Again all the people filed by, this time giving me strange looks. They almost seemed to be saying, "Don't you want to stand and get in line?" Vic had gone down to see that my chair was brought around to the foot of the stairs. He came back with a man and the weird chair. Now to work again. I was transferred and carried down the stairs and transferred again into my waiting wheelchair. Now for the bags. When they showed up Vic had to find a porter to take us to the cab. Again the ride with who-knows-what-kind of driver. He took us to the lobby of the motel that was to be our home for a few days.

After we registered and settled in to our room we went to look over Las Vegas. We walked a lot during the next few days. Down off the curb, across the street, up on the curb, walk a block and down and up all over again. We did this hundreds of times.

At first I didn't look forward to being bounced around so much. But it did have an advantage. Each time I was tilted back to climb up a curb, the pressure on my seat was for an instant relieved. Going off the curb shook up my whole being, but it also bounced me off the seat for a second. I was becoming quite relaxed about the process. Tilting back had been very

frightening, but it became great fun. Vic was also making a game out of the necessary evil. A couple of times I became frightened, but I always came safely upright again.

Then one time, when I thought Vic was really getting daring and I was laughing at his silliness, the chair didn't come upright. There I was in a sitting position, but lying on my back. The chair had tipped back in the middle of the street, with me in it, laughing insanely. It seems that Vic had become so accustomed to changing the position of his hands on the handles that he didn't think about it anymore. I guess that one incident really made an imprint on his mind. In all our years of walking, we haven't had a repeat.

The weather was warm enough for me to go in the swimming pool. Going in was fairly simple. Vic managed to hold me in a sitting position on the edge of the pool while he slipped into the water. Then he pulled me in facing him. Being in the water was a wonderful sensation. I felt no pressure, and my left arm moved quite easily, still slowly but the response seemed better. After we had played around for a sufficient time, I wondered how Vic would get me out. He put me in a sitting position in the water and just carried me out to awaiting lounge chair. It seemed to me that I felt very heavy when we came out of the water, but after the taxi transfers, Vic seemed to possess great strength. This way Vic discovered he now had the strength and coordination to carry me by himself. That turned out to be valuable for many future transfers.

In the evenings we rested by attending dinner shows. These places were set up to feed a maximum number of people in a short span of time. When my wheelchair took up more room than was allowed, it caused a bit of a problem. It caused more of a problem when they put us at a table for two, where we sat across from each other, instead of sitting next to each other. We need to be within reaching distance for Vic to feed me. So we have to sit at a 90° angle. Vic usually ended up using space that was allotted to the waiters. To put the wheelchair there would be quite impossible. Having a waiter trip over a wheelchair was not in the plan. All this and I had to be put into a position where I could watch the show. It was a bit easier to move Vic when the show started. At the end of a day I was more than ready to be put on the alternating air mattress on the motel bed.

After three days of this highly irregular schedule it was time to go back home. Another taxi ride, more fiddle-faddle with boarding the plane. The peculiar boarding wheelchair seemed old hat by now. At least, with the element of surprise removed, I could manage to keep my emotions under control this time. The flight was again a normal one for the seasoned traveler. The wonderment of my being in a plane had not worn off. I looked at everything within my range, but was not shocked this time by the frustration of not moving at will. When there was something special to see out the window Vic leaned me over and turned my shoulders. We were served soft drinks. I had a little through the straw we had remembered to keep with us. But only a little. Carbonation causes me great distress and I was limiting liquids during the flight. We came back in the evening. Being able to see the lights of San Diego was a great thrill, as was the exciting landing at Lindbergh Field.

Vic again left quickly to get my wheelchair and bring it around to the foot of the stairs. I seemed to be left alone for a short time after the long line of passengers disembarked. Soon Vic appeared with an airline employee and my own wheelchair. He gave some explanation which I

didn't understand, but there was no time for questions. Quickly I was transferred into my own chair and taken out to the top of the stairs. I thought Vic had talked the airlines man into letting him bounce me down the stairs. But no, the man was undoing a chain and motioning for us to go onto a small platform surrounded by a guardrail. I couldn't see beneath us, only to the sides as far as my head would turn. As far as I could see there was nothing holding up this small island of steel. When we were secured with the fourth side of the guardrail, the "thing" began to move. We were lowered very gradually and soon the ground was in sight. I still couldn't tell by what means we were magically taken off the plane. When we were being unloaded I caught a glimpse of the big forklift that had been doing the work. I was unloaded just like a load of cement blocks.

It was good to be on familiar territory again, but it seemed a bit like we were stepping from fantasy to fact. Back to the routine life.

TOURING EUROPE in a WHEELCHAIR

We now felt confident enough for a big venture, especially as Vic had discovered in Las Vegas that he could lift me into a car by himself. This did away with the necessity for a lifting sheet and the teamwork that had been part of getting me into the front seat. The next summer we took just weekend trips, but the following spring we made arrangements to fly to Europe. I've looked forward to such a trip for years. Vic has relatives in Holland. He can speak and understand Dutch fairly well. He has a passable knowledge of French and German.

We were to fly to Amsterdam, and later to leave again from there. We would have five whole weeks in which to do as we pleased. It would have been very difficult for us to keep up with a tour group. Our way, we didn't have to plan very far in advance. If we liked a particular place, we stayed for a while. Before the trip, we got all kinds of books from the library, and decided generally which countries we would like to visit. We bought tour guidebooks of these countries and carried them all over Europe.

Other preparations for the trip included the usual shots and passports. The shots left a useless arm very sore for a few days. The passport presented a bit more of a problem. You're required to sign your name on the small passport picture. I can write now, but only sprawlingly. My signature would never fit. They finally decided that Vic could guide my hand. The signature looked like his writing, but they accepted it.

We had to have the capability of managing to handle me and our luggage with only Vic's one pair of hands. To accomplish this Vic built a hardwood and canvas luggage rack and attached it to the back of the wheelchair. On this rack we could stand two suitcases on end and strap them to the wheelchair. I could carry a smaller bag on my lap. Still there remained one more, a fairly good-sized suitcase. Vic put a long strap through its handle to be slung over his shoulder. There was also a canvas gadget bag that fitted on the handles of the wheelchair. This way Vic still had his hands free to push the loaded-down chair. The sight of us when we were completely on our own was really quite unbelievable!

Our housekeeper and her husband moved in while we were to be away, and took care of

the children. Our house was being remodeled and was supposed to be finished by the time we left. When we left, the remodelers were far from finished. When we returned they were still working. That must have been a frightful time for the people who stayed home. We got away and found it possible to leave our worries behind. But five weeks later they were still waiting for us.

We took a cab to the airport and boarded a plane to Los Angeles, where the charter flight originated. At this point our ground transportation problems were solved by Vic having a last-minute business conference. A car was waiting and picked us up with our baggage. After the conference we were delivered to the departure terminal. We still had some time on our hands. Everything seemed strange already. Seventy-five percent of the people nearby were speaking Dutch. We exchanged some of our money for Dutch currency so that when we arrived in Amsterdam we would be prepared. I had a last minute trip to the bathroom. There was still extra time.

All this extra time was most unusual for us. We got some hot chocolate out of a vending machine. I had second thoughts about drinking it, but concluded that dehydrating myself could create more of a problem than two people in a one-person bathroom. We found ourselves watching people. This is kind of fun when the people are speaking a foreign language. Vic found that he could understand an amazing amount. They sounded like just so many chipmunks to me.

After a short while someone came up to us and asked us to wait by a particular door. Another wheelchair passenger was there. She was quite a bit more animated than I. The wheelchair contingent was escorted to the plane. I was surprised when they took us aboard in our own chairs.

Vic and I had sixth row seats, but we managed quite well with an empty plane. Vic got me settled and went to see that the chair was put aboard. All the mobile passengers started coming aboard, still sounding like chipmunks. In fact, the chirping was taking on an exciting quality. There were three seats on each side of the aisle. Fortunately no one tried to clamber over me. They would have received a rude shock when they found me uncooperative.

Vic came back aboard amongst the stream of people. It was a relief not to be alone in this unfamiliar situation. Even after Vic returned, no one tried to sit in the third seat. When the line of people stopped coming we discovered that there were many empty seats. We were going to have a little more room than we anticipated. This was good news since I really hadn't figured out what I was going to do when sitting became unbearable. As it turned out, I could put my feet in the empty seat and my head in Vic's lap and be turned on my side; at least until Vic got numb. Then Vic could switch to the other seat and I could be turned the other way.

We left on schedule, made one fuel stop in Chicago, and headed for Amsterdam. Hours and hours of only ocean below, the only difference being whether the water was smooth or rough. A couple we knew as casual acquaintances from San Diego was on the flight. One of the few conversations we had was with them. They were two of the few people I could understand. It was like being in a completely different world.

It seemed strange to hear the stewardesses change languages as they encountered different people. They seemed to know just from a glance which language to use. After many hours and several meals and snacks, I couldn't afford to put the bathroom problem off any longer. It's a good thing I had become insensitive to this type of notoriety. Vic had to ask a stewardess to let us know when the room was empty and to keep the aisle clear. We also needed her help with the door.

At the appropriate moment Vic pulled me up into a standing position and carried me, bear-hug style, down the aisle of a loaded plane. It's a lucky thing we were only six seats away. I'm not sure we would have made it much farther. Luckily I was wearing a pantsuit.

Once inside the tiny room there was the problem of managing clothes. Vic made light of it by saying that at least the small room could hold me up while he worked. When we made it back to our seats we were both exhausted. But there was still much time to recover from the ordeal. A few more hours, and a few more meals and snacks, and we began to see what I thought were a group of islands. The islands got thicker and turned into solid land. We were over Scotland. We flew on. More water, then we saw land that seemed to get even greener and was broken up into small plots. But the plots all had water around them and they were even greener than photographs can show. There could be no other place like this. We had arrived in Holland.

I have no memory of the landing. I must have been overcome by so much green everywhere. Vic left me to get the wheelchair, and came back with the news that I would have to use an airport wheelchair until the baggage arrived. My wheelchair has an especially high back and gives me the support I need to sit up. Vic stayed behind me and gave me moral support until I could be transferred into my own wheelchair.

There were no porters. This is true of most of the places we visited. So, we used our own peculiar system for transporting baggage. We found a cab which took us to our one night reservation: a typical airport motel. All very modern, inexpensive construction, made to look elegant. We had our first European meal in a very Americanized coffee shop that was part of this fairly isolated complex. This was about the last business we encountered in the Netherlands with open space around it.

The next day we made our way into the crowded city of Amsterdam. I was impressed by the indescribable number of bicycles, the crazy, impolite, small cars, the strange architecture, and the number of women dressed in miniskirts and maxi coats. The first order of business was to find a place to stay. After wandering around aimlessly, loaded down beyond description, Vic came quickly to the conclusion that we needed some help from the tourist service. There we made reservations for a room on the ground floor of a small hotel.

We decided we needed a car in order to be able to visit a goodly number of relatives. The bags were loaded into the rented car. Loading me into a medium sized auto required quite a technique. Fortunately, the front seat back could be laid flat. After I was in, Vic had to run around to the driver's side to put me into a sitting position. When I was in, there wasn't much

room to spare. To get me into a small car would be next to impossible. The collapsible seat did have another advantage. When sitting began to hurt too much, the pressure could be relieved by laying me down. This left me with my head hanging awkwardly without support. Rancho Los Amigos experience reminded me that this was uncomfortable but not harmful.

We drove to the small hotel. Vic took some bags in and made a discovery. The ground floor was half a story up a very wide entrance with extremely narrow treads of red-carpeted stairs. Going up or down those stairs was a twice-a-day thrill.

It turned out to be a delightful place to stay. It apparently was two very old mansions, overlooking a beautiful small park that had been converted into a small hotel. The two houses had been connected on the second floor to form a dining hall. But the narrow stairs were a bit much for us to manage every morning. Yet, breakfast was included with the room.

A family seemed to be running the business. Every morning the father came skillfully down the steep flight of stairs, carrying our tray. It was loaded down with everything we could possibly use for a typical Dutch breakfast. He not only brought the tray to our room, but very carefully laid it out on a table in the room. We always had a boiled egg, many different kinds of bread, sliced ham and cheese, whipped butter, and a pot of tea. Every day there was a different kind of jelly or cheese spread. This was wonderful. We could massacre my food in the privacy of our own room and know that we were not ruining other appetites. Also, I eat extremely slowly, and here I felt I could take as much time as I needed.

And I felt brave about trying food that I hadn't eaten for years. At home I had the privacy that was needed, but I also had a convenient blender. Now I discovered that I could eat crisp but crumbly foods by taking very small bites and endeavoring to keep the food in the front of my mouth and chewing it with my incisors until it was thoroughly mixed with saliva. Then when it escaped to the back of my throat it wasn't dry and the chewing action had prepared my throat for swallowing. Of course, I discovered all this after many pieces of Dutch Rusk had gotten out of my control and scratched all the way down my throat, causing a choking fit. I had already learned that I could manage soft breads lubricated by jelly. Soft cheese was manageable, and egg yolks could be "squished" (Vic's term) with a fork. Vic ate a lot of egg whites that week. Ham is difficult even when blended. Things were not packaged in individual portions, as they are so often in America, but served in tiny little salt and peppershakers, delightfully graceful creamers and sugars and tiny glass butter dishes. Sometimes the jellies and cheese spreads were in individual paper cups and were obviously bought this way. A small amount of indecent efficiency had crept into the Old World way of life.

While we were in Amsterdam we took a canal boat excursion. Men try to lure you onto the boat like carnival barkers. There are several steps going down into the canal excursion boats. These steps are not wide enough for a wheelchair, nor is there room enough on the boat for a wheelchair. But by now I had learned that little problems like this didn't influence Vic when he set out to do something. He sized up the situation and decided how the task could be accomplished. Then he instructed the more than willing canal boat pilot how he could help. Vic placed the wheelchair in just the proper position, picked me up into a standing position by the bear hug technique, stepped partway down the ladder, set me on the top step, asked the helper to

hold on to my shoulders from behind me. Then he went to the bottom of the ladder, got a new hold on me and, with everyone trying to help, lowered me into the boat. He asked the helper to put my air pillow on the front bench and sat me on it. Then he sat down next to me to keep me from falling over. The wall of the boat held me up from the other side. Fortunately, it was there. Vic was also taking pictures while trying to hold me in place with his body weight.

After we got on, there was quite a group gathered behind us. The boat filled up fairly quickly and we were on our way. The lady tour guide pointed out the points of interest in both Dutch and English. The Dutch came first. I listened to the Dutch spiel and decided that I almost understood. After the English translation I knew I'd been fooling myself.

I really don't remember the combination of antics that got me off that boat but I do remember amazement at the fact that I had taken the canal tour and was safely back in the familiar wheelchair.

I had spent a lot of time thinking about exactly what I should bring on this trip and had typed out a list which we checked off when we packed. We put the bedpan among all the strange items to be packed. When we unpacked in that first airport motel there was no bedpan. We had managed the first morning but now we were near a drugstore and I am too much to carry to the bathroom every day. There was still well over four weeks to go.

So Vic left me in the room and went the few blocks to the store. One word he hadn't learned in Dutch was 'bedpan', and especially not 'fracture bedpan'. He explained its use and they seemed to understand and went after the article. Vic thought to himself, they'll come back with a contour pan and I'll have to take it. But he was in luck. The first item he was shown was a very good, tough, plastic, large sized fracture pan. It has been in service ever since.

We just happened to be in Holland with a car the week the tulips were in full bloom. So, of course, we went to the famous Keukenhof Gardens. There we were engulfed in color. Everywhere we turned the tulips and hyacinths were in a more beautiful arrangement than we had just seen. Every nursery had a display and each one outdid the other. I decided tulips were a very appropriate flower to go with the hardy people. Here the tulips were in full bloom in sunny, but cold weather. And the people mostly wore unbuttoned coats or sweaters. A few, including Vic, were in shirtsleeves. Meanwhile, I was bundled up in a sweater and a wool cape and I was still cold. The heavy wool cape was purchased for the trip and proved to be well worth it. Even the insides of buildings seemed a bit chilly to me. When we were inside, the cape could be unbuttoned and thrown back over the back of the wheelchair. When we were about to go outside it was already on me, ready to button up for braving the cold.

Amsterdam, being below sea level and right on the ocean, is a cold and windy place. I had been warned, but feeling it for myself was still a shock. After spending a few days there we bought a blanket to put over my legs. The women who wore maxi coats were pretty smart, after all.

Another day that week was spent at Madurodam, which is near den Haag (The Hague) a short drive from Amsterdam. There they have many tiny replicas of buildings and other scenes

in the Netherlands. The replicas are perfect copies. If you take a picture that includes people, they appear to be giants in a typical Dutch setting. This seemed to be a very popular attraction with hundreds of people in attendance. It obviously was not meant for wheelchair tourists. There were a goodly number of steps going down into this outdoor exhibition. At the bottom there was a large flat area where we could sightsee. We had to skip a portion near the end that had a fairly steep dirt path. The replicas were small enough to see over when sitting down. Again I had the frustrating experience of trying to lean over and nothing happening. Oh well, it was an amazing feat that I was there at all.

After a week in Amsterdam we decided to move on. Our next stop was Paris. We turned in the car and headed for the train station. It was nearby, fortunately, since we were now loaded with all our possessions. When sidewalks were too narrow we became part of the vehicular traffic. We, of course, could not manage stairs but were able to use driveways, or little ramps that were probably meant for the many, many bicycles.

We had previously purchased Eurail passes that allowed us to ride trains as much as we wanted for a month. Our tickets were taken care of. We purchased a map of Paris and a train schedule. After locating the proper train and determining that we had a few minutes to spare we began to attack the problem of how to get aboard. The first thing to do was unburden ourselves. Vic put down his large shoulder strap bag, and then took the bag from my lap. At this moment he looked away to answer some stranger's question. He was out of my limited field of vision and I thought he was behind the wheelchair. I wondered why he was tipping me back but said nothing. His motives usually became clear after the fact. When I had tipped back too far I realized what was happening. The two suitcases still strapped on the back were pulling me over. This fright gave me the power to scream. It was too late but the two suitcases did serve to break my fall. This experience showed us that things must be done in the correct order.

I attracted enough attention that we didn't have to snare help to get aboard that time. One person helped load the bags on board while another person helped Vic load me, chair and all, onto the small platform on the train. Now we were aboard. The train could start. Vic went to find our reserved seats and stow the luggage. Then we moved into the compartment with the familiar bear hug carry.

Riding trains proved to be far preferable to having a car. Here I had room enough to use the air pillow. The trains went through very scenic country and had big picture windows. We could both enjoy the view. Vic had time for studying maps and train schedules and time for conversation that was not possible while driving. The struggle to board now seemed worthwhile.

While in Amsterdam we had made reservations at a hotel in Paris that was within walking distance of the train station. There were no ground floor rooms so we made sure the place had an elevator. Walking from the train station to the hotel, loaded down with bags seemed like an eternity. We finally made it and registered.

There we discovered that the elevator was too small for the wheelchair. We solved this problem by having Vic transfer me to a straight back chair and hold me up for the elevator ride. The bellboy brought the folded-up wheelchair up the stairs and met us by the elevator. We got

halfway along the hall and it suddenly narrowed down. Now the hall was too narrow for the wheelchair. Vic might have just left me there, but I needed to use the bathroom before having dinner. He carried me down the narrow hall and dumped me on the bed. He was exhausted.

The following morning we decided to try a different technique. We would go down the stairs. This is normally fairly simple and Vic can handle it by himself, but this was a narrow circular stairway. Vic and the bellboy thought that together they could handle it. On the curves the chair had to be tilted. We made it, but that's one sensation I can do without.

Vic remembered a hotel where he'd stayed before in Paris on a business trip. He thought he could find the hotel. He did. It had an elevator that could accommodate me. The halls were wide enough. They had a room. He left me there and took a cab for the bags. We knew from then on we were in for the more expensive hotels.

While we were in Paris we visited most of the usual tourist attractions on foot. Some of them were quite far away. Walking was simpler than the fussing needed to get me into a taxi. Versailles and Fontainebleau were a bit too far away. For these we took trains. First of all, we were given the information that the train substation was much closer than the main station. This was quite true. They neglected to tell us that at the substation the train was in a subway. To get to it we went down a very long, wide, concrete stairway. The stairway was wide but each step shallow in depth. For the first time I experienced fear going downstairs.

In a few minutes the train came by. We tried to board but discovered that the door was too narrow. We had to let that train go by. We were ready for the next one. Vic carried me aboard. Some stranger helped with the folded up travel wheelchair. Fortunately, at the end of the line, there was a little more time to disembark.

By this time we were accustomed to the cobblestone streets. Some of the newer ones were quite smooth. Here we encountered the huge courtyard of the chateau. The cobblestones could have been the originals. Even though I was tilted back and traveling on the larger wheels, I was still up in the air a good part of the time. I didn't need to be 'depressed' that day.

Going upstairs to the chateau was always quite a thrill. Someone would usually want to help. This was wonderful, except that very often the volunteer didn't speak English. Vic's French was poor. The person would lift, not push, the foot of the wheelchair. This simply transferred most of my weight to the handles, which Vic had to carry. The people were so eager to help. I'm not sure Vic would have told them had his French been perfect.

The memory of the great effort was soon blotted out by the overwhelming elegance surrounding us. Each room more fantastically beautiful than the last we had seen.

After three days in Paris we were ready to move on. We next headed for Tours. Another train ride. We soon became experts on the layout of European train stations. We found two principal types. One is laid out on the ground floor like a many-pronged fork, with each train coming to the end of its track. We had no problem with these. The other type has a number of parallel through tracks at ground level. As a passenger you walk down a tunnel crossing under

the tracks until you reach the right one, whereupon you climb a long staircase to the platform along the track. There would have been many climbs up the stairs, tiring for Vic and scary for me, if we hadn't discovered freight elevators. We soon learned to look for them before tackling the stairs. Usually the freight elevators end in a separate tunnel leading to the baggage room. We entered and left many train stations with the baggage.

In Europe the trains are one of the most popular means of transportation. There are many trains and they are almost always on time. Quite a number schedule three- to four-minute stops. We learned not to try to catch those when we were traveling with all our belongings. It was enough of a trick to get on board during these short stops when we had just ourselves, a bulging gadget bag, and the wheelchair. Any time we planned to catch a train, it paid to get away from the crowd and enter a car down the track. We tried to figure out just about where the third car would stop, and plant ourselves there. We were careful not to stray too far from people, because when the train did stop we had to quickly snare some help. .

One time we tried to ship our luggage to save handling **it** during boarding, but found it not possible to check luggage within a country.

The baggage cars on passenger trains are almost always empty. We know, because one time the only help we could manage to snare were train porters. They took one look and directed us to the baggage car. This happened one time after we had just taken Europe's finest train, complete with electric doors between cars. Baggage cars had two disadvantages: There was no place for Vic to sit down, and neither of us could see the scenery.

By this time we learned to make reservations in a hotel close to the train station and to inquire whether it was possible to reach the room in a wheelchair. Often it was necessary to remove the foot pedals to make the wheelchair fit in the elevator. We found that a tape measure was very useful for measuring train doors and elevators.

The hotel in Tours was close both to the station and to many tourist attractions. The first day we walked around sightseeing, and found a beautiful cathedral. Even after seeing Notre Dame it was still fantastic. We also found that several trips to chateaus were available for the following day. We signed up for a bus tour of four chateaus built in different periods. I thought we were nuts but had learned that Vic thought nothing was impossible. We found out that two large people going together into the doorway of a bus are nearly as comical as two large people trying to get into the back seat of a taxi. We made it with a boost from the driver. I was placed in a front seat.

The first chateau was built when defense was important. It was on the top of a fairly steep hill - too steep for the bus to climb. Vic and one of the men on the tour pushed me up that hill. We stayed on the ground floor this time. The tour lasted all day with the last chateau (still in use) built on level territory.

Next, we wanted to go to Marseilles. Very late in the afternoon we tried to make train reservations for the following day. The reservation clerk had left for the day. The person there didn't know how to take care of it, nor did he speak English. He sent us to another person who

had exactly the same problems. All we could understand was 'impossible'. We went back to the bus tour office where a lady who was bilingual straightened out the problem by phone. Then, back to the train station to pick up the reservations. The next day we found we didn't need the reservations. The train was practically empty.

The ride to Marseilles was charming. The scenery included beautiful countryside, lovely homes, and cliff dwelling homes. This is where rock had been removed to build the chateaus and left caves in the cliffs. People built little entrances to these caves and have beautiful and safe homes inside.

After arriving at Marseilles we started our usual walk to the hotel, loaded down in our usual fashion. We encountered a staircase going down. This one must have had two or three hundred steps. A man passing by offered help. For a split second I thought Vic was going to accept, but we looked for the vehicular traffic and went around that way. We had a map of the city so we could find our way. We even helped another tourist with directions.

Marseilles is a city of litterbugs. We used it only for its hotel. In the morning we took a train east to Cannes. About halfway there we could see the blue of the Mediterranean. In Europe trains seem to take very scenic routes. For a while we walked around and looked at the luxurious yachts from all over the world and the gorgeous private beaches. Then we discovered it was possible to take a boat to the small islands just off the coast. The sea is clear and blue despite the many boats. This boat had an entry level with the dock and I could stay right in the wheelchair. We chose a trip to Sainte Marguerite Island; a beautiful place with windswept trees. When first on the island, we saw a signboard map with the various points of interest. We went in the opposite direction from the main part of the crowd, intending to retrace our path after seeing that end of the island. At first the going was easy. There was a blacktop path. When the path ran out the going was still fairly easy. The land seemed to be rather gravelly. The island looked so small so we decided to just keep going, stopping to take pictures now and then. Gradually the terrain began to climb. By now we were over halfway around. We thought it best to keep going. The land seemed to be climbing faster now. We walked and walked until we could see two ways to go. One of them was steeply downhill, but it seemed like the way back to the boat landing. It looked good until we came upon some wooden steps going down. Vic went to investigate what was at the bottom. All he could find were more stairs going up. So we were forced to turn around and retrace our steps. The going was really rough. Vic had to push the chair a few feet with his arms, move both feet and then repeat the process. Eventually we met a man who offered to help. He was full of vigor, grabbed on to the chair and started pulling. Now Vic had to keep up with him. Mercifully we eventually came back on the blacktop path. We thanked the man and Vic took a well-deserved rest before continuing on our way.

That night we returned to the hotel in Marseilles. In the morning we went west to Nimes to see the old Roman arena. It is still in use as a bullfight arena. I had to be taken in a special entrance to see inside. There I watched a young man practicing without a bull, while Vic climbed around the rest of the structure and took pictures. I never did reach the center. The inner pathways were fascinating.

The following morning we made our way slowly to the train station. Laden down with

our belongings and walking uphill didn't make for speed. We planned to go to Grenoble, spend part of the day there, and then catch a train for Geneva. We got to Grenoble, put our bags in a locker, and started to look the place over when I suddenly got a now familiar grumbling in my bowels. Since this had been a suppository morning, the grumbling meant something and there was no time to spare. We were not looking forward to another messy clean-up job or the dripping of wet clothes in the bathroom all night. We headed for the nearest hotel. Service stations were a rarity. We had to take an elevator to another floor. Wonder of wonders, it was large enough. We made it just in time. With that worry out of the way we could really enjoy the rest of the day.

Our first day in Geneva we spent shopping. Even in Geneva the shops seemed small. I backed into many tight fits. I wondered how a wheelchair would fare in Switzerland, but small shops had not been my concern. Actually my fears were unfounded. We had less trouble with transportation there. Between the trains, steamers, and aerial trams I had nothing to fear. Actually aerial trams are quite easy for a wheelchair. I did feel a bit of concern at the top, for the person doing the pushing.

The second day in Geneva, we took a bus tour back into the French Alps, to Chamonix. It is located in a valley near Mt. Blanc, one of the most spectacular scenes in the Alps. The day was clear but overcast. When we arrived we took the aerial tram (teleferique) from Chamonix to Aguille du Midi, a needle-like rock over 10,000 feet high overlooking Chamonix. I in my wheelchair, Vic, and a group of Japanese tourists boarded the cable car. After a short climb the cable car suddenly stopped and swayed. Since none of us expected that, it gave me quite a fright. But it started up again with no sign of trouble.

Halfway up we transferred to another cable car, somewhat smaller than the first one, but still large enough for the wheelchair. Of course, each station had a number of steps up which Vic had to pull the chair. But there were plenty of willing helpers.

At the top we found ourselves inside a large hollowed-out rock with a snowstorm outside. Vic took me up to a warm snack bar while he went exploring. Then he came back and gave me a tour of the tunnels and a short exposed bridge between two large rocks. We couldn't even see the ground under the bridge due to the snow coming down. It was an eerie feeling to be so isolated in the clouds.

On the trip down we could only see a short piece of the cable holding up the cable car until we suddenly broke out of the clouds to see Chamonix far below. After we arrived we walked around to see the many interesting houses. We took another short trip on a cog railway to a large glacier (Sea of Glass). But the wind was blowing cold and I stayed inside the railroad car all the time.

The next day we took off on a train trip again. Our next stop was Lucerne. I believe this was my favorite place. There was lots to do and see and the hospitality of the Swiss people was genuine. They couldn't do enough for you and some of my special problems were a challenge they wouldn't let go unconquered. We stayed five nights, and would have stayed longer had not our time been running out.

Here we hit our first bad weather. But that didn't stop us. We could still ride trains and see spectacular scenery. If the terrain gets too steep for a normal train, the Swiss simply build a cog railway. We rode some little trains where not too many tourists go. We saw genuine Swiss mountain people with their baskets of cheese, bread and wine.

On our way to Lucerne we went through Interlaken and got some very clear pictures of the Jungfrau. When we went back to take a trip to the Jungfrau, the bad weather had just begun. We did take the trip to Kleine Scheidegg, where the railway to the JungfrauJoch begins. It was already in the clouds. Between the altitude, the patches of snow, and the bad weather, going became a little rough even without a wheelchair. It was time to move on. There were still many things to see and do before the return trip.

Next we planned to take the Rhine steamer from Mainz, Germany to Dusseldorf, Germany. This trip was included in our Eurail passes. We tried to get a hotel reservation for Mainz but found the city to be crowded by a convention. So the plan was to go to the nearby town of Mannheim for the night, and early in the morning to catch a train for Mainz. At Mannheim it was pouring so we decided to take a taxi to the hotel. We got thoroughly soaked getting ourselves and our belongings in and out of the taxi.

At last we were in the shelter of a warm hotel lobby. It seemed fairly crowded. When Vic got to the desk they gave him the name of a nearby hotel. We were part of their overflow reservations. There was nothing to do but put back on our wet plastic raincoats and brace the weather. A taxi would have been useless; we were already as wet as possible. So we walked and giggled our way through the rain. It seemed the clerk had given us bad directions. It took twice as long as necessary.

We finally arrived and were confronted with a set of concrete steps and average size revolving doors. The steps we could have managed, given enough time, but our handy tape measure told Vic that the chair couldn't enter through the doors. Vic went in for some advice. When he came back he had registered and was taking me around back to the garage. From the garage we were taken up a service elevator and led through a maze of catacombs.

To my amazement we came out in an old, extremely elegant hotel. It must have been built in the days when space was of little concern. The halls were extremely wide. The carpeting was old but of the best quality. The elevator was old but huge. I felt as if we didn't belong in this old world elegance. Especially not dripping wet and laden with wet luggage. Despite our appearance we were treated regally and led into a monstrous combination bedroom and sitting room. When the bellboy left we discovered we were in a corner room with two large balconies. In one direction was a view of the neon lighted town. The other balcony showed a view of a very old park. Further investigation showed we had a bathroom the size of a small bedroom and completely tiled.

After we dried out a bit we went in search of dinner. The hotel had a Chinese restaurant in the basement. The elevator went only to the main floor. Steps going down were not a problem. The door at the bottom was too narrow. Again we were led to a back entrance and went through the kitchen to a private alcove. Here we had a typical Chinese meal, served in the

grand manner. Then out through the kitchen again.

The next morning we left very early to catch a train for Mainz, out through the catacombs, service elevator and garage. At Mainz we couldn't check our belongings for we were to end up at Dusseldorf. There was not too much time before the Rhine steamer was due to leave. We got a map and discovered the landing was not far away. Again we became part of the vehicular traffic and went as fast as we could to the dock. All the way we had to keep readjusting the bag in my lap while we were moving.

The gangplank was drawn up just minutes after we were on board. Now we could relax. This was to be an all-day affair. We got a little brochure, map style, that told us about all the castles along the Rhine. We kept track of where we were, investigating the boat, had lunch, watched the many vineyards and listened to the numerous German teenagers.

It got to be mid-afternoon and the bathroom problem was upon us. We thought we were in trouble now. There were no small bathrooms on board. We went to the attendant in the large public ladies room and told her our dilemma. She asked us to wait in line. We thought she was clearing the room. Soon she motioned for us. We found that it only meant there was an empty stall. The other women just went about their business paying us no mind, except maybe a few Americans who were surprised to see Vic in there.

We continued with the relaxed sightseeing. Dusseldorf has many modern buildings and wide streets. We saw some of the city late that afternoon. The following day we took the train to Cologne. There a very modern train station is built right next to the imposing, ancient Cologne cathedral. All around the cathedral are signs of modern construction. We were taking pictures of this rather odd combination when once again I felt ominous rumblings.

Vic rushed me to a nearby hotel and asked if I might use a bathroom. There was a lot of discussion in German, while I was frantically trying to control very weak muscles. Finally, the clerk gave Vic the key to a room that was not ready for its next occupant. We made it just in time. When it was all over Vic explained that he had used an unfortunate choice of words. When he asked for a bathroom the clerk thought I wanted to take a bath.

Now we were ready for our visit to the beautiful cathedral building. More contrasts were apparent on the inside. Some of the bombed-out windows had not yet been replaced. Some were obviously a copy of the very old stained glass and there was one very large window that had been replaced with stained glass in a very modern art form.

We decided to spend our last few days seeing other parts of the Netherlands and visiting with relatives we had missed. That afternoon we took a train to Eindhoven where one of Vic's aunts lives. The Netherlands is such a small country that we could stay anywhere and still get to Amsterdam for our return trip. We chose Rotterdam. From there we could accomplish all the last minute visiting and sightseeing. We had learned to strap the folding wheelchair together, with me in it, to make it narrow enough for the doors on local trains. One night very late, on the way back to the hotel in Rotterdam, we went over a curb. I felt something snap, and the chair became even narrower. At our hotel Vic examined it. One of the main cross struts had broken

and the straps were keeping the chair from completely collapsing. The next day we were to visit an aunt in Den Haag. We made it to her home and, while visiting, patched up the chair with some pieces of steel and wire. The patch job would see us home. I was no longer being squeezed but was in fear of becoming completely immobilized.

The following day was the flight home. We made a fuel stop in Montreal, where they let us off the plane into a small part of the airport. After we and the plane were refreshed we were on our way again and landed in Los Angeles. Here again we were the last people off the plane. When we got into customs it was jammed. Being in a wheelchair does have some compensation. They took one look at us and sent us up to the beginning of the line.

Now to find our way back to San Diego. The planes for San Diego were on the other side of the very large Los Angeles airport. Vic didn't dare carry the luggage on the crippled wheelchair. Some people who had been on the plane with us had a car in the parking lot and offered to bring our luggage to the other terminal. We walked around and checked on plane times. Then we waited for the car to come.

We waited so long that we missed the plane. Vic decided to walk back to find out what had happened to our baggage. He left me there in case they showed up. He left me on a traffic island in order to be in view if the car with our baggage passed by. It was late in the evening and headlights from the automobiles seemed to point at me and at the last instant, rush past. It was early in June and the night air seemed very chilly. I had visions of something happening to Vic and my not being able to communicate, or even continually being ignored.

Vic had just started to walk back to the terminal where we left our baggage when he was stopped by the police to check his breath. They apparently thought he was inebriated when he stumbled on a sprinkler head just as he came in their view. After twenty minutes or so, which felt like a lifetime, Vic showed up with the luggage. The car belonging to the people who had volunteered to help had gotten stuck in the parking lot.

We were just barely in time for the next plane. We were told to wait for the next one because there wasn't time to board me. Vic talked them into letting him board me in my own chair by promising not to sue if anything happened. We made the plane.

All the time we were in Europe I had had a reoccurring urine infection which I kept under control with medication. It was acting up again. I couldn't do anything about it now. It seemed like an eternity until the 'fasten your seat belts' sign went off. In a short time we were home. It seemed like it was more difficult to travel from Los Angeles to San Diego than it was to tour Europe in a wheelchair.

MY CONCLUSIONS

I once heard Dale Evans say on T.V., "God never puts anything on a person that they don't have the strength to endure." I'm not completely sure that I agree. I've seen a great deal of human suffering and I'm not convinced that all of it was caused by God. Some of it couldn't be explained, but the rest of it was clearly caused by man's oversight. Furthermore, some of the

suffering was not being endured. Those who couldn't endure tried attempts on their lives or simply gave up. It didn't seem to matter to them whether their particular trouble could be explained or not.

Yet, I'm sure that I would never had had the time or the motivation to undertake this writing project if my life had gone as I planned. I certainly wouldn't have had the subject matter. Somewhere I heard someone say that God uses man's misfortunes. At the time it didn't make sense to me, but I'm beginning to understand.

I really don't know whether my belief in God has helped me or not. I used to question my belief and I thought that if something dramatic ever happened to me I would know just what I believed. Well, I'm still wondering. Having grown up with the belief, I really don't know what it would be like to disbelieve in God. I do agree with what I think I understand from a sermon: to take your problems to God alone is not enough; they must be shared with another human and with God.

Natural behavior from anyone makes me feel most at ease. I believe I'm more comfortable with people who were my friends before the surgery, because they tend more to be themselves when around me than does a stranger, who isn't sure quite how to act and who tries too hard to make small talk. There are a few exceptions, but they tend to be individuals who are used to working with all types of people. Then there are some who were acquaintances before my surgery and have occasionally seen me since who still can't seem to understand that only my motor nerves were damaged. They will come up to us and say to Vic, "Poor thing, does she understand what is going on?"

No, no one has been deliberately hurtful or callous, but they can be very irritating when they're trying to be helpful. For example, I usually have a long list in my memory of things that need to be done; more than can be accomplished in one weekend. Our nurse and housekeeper can also see what needs to be accomplished. They're torn between feeling it is their duty to inform me and waiting to see if it's accomplished without saying anything. Finally, their impatience gets the better of them. They make a big plea for getting the matter accomplished. I decided to ignore them and have my own priority list. Then when their pet project does become a reality, I almost wish it hadn't. Without meaning to, they over-expound on what a wonderful suggestion they made.

I have no plans for further writing for two reasons. First, this is probably the only subject on which there are not thousands of people much better qualified than I. Second, even though I'm right here so many things are beyond my control when I'm writing. When I first started, I got a lot more done in a given amount of time because I typed while everyone else went to dinner. That was really too great a sacrifice, for then I gave up knowing what was happening in our family life and just about turned over the privilege of raising my children to someone else. Now, most of the time I have available for typing seems to be consumed in writing letters, lists or notes to employees and family. There are times when it's important to get my meaning across before what I want to say can be misconstrued. Somehow these things need to be done before any creative writing is accomplished.

Before my surgery, some people considered me to be a fairly patient person. Compared to the patience it's necessary to exercise now, I wasn't. And of course, now I'm not as patient as is necessary. I'll need much more than five years to develop this talent. Besides, as I become more patient, even more seems to be expected of me. Sometimes I'm told I lose patience now more often than I did before surgery. Possibly this is true, but while patience very seldom shows, impatience always does.

Do I ever get bored? The answer to that should be, no, there is too much to relearn. But a more truthful answer would be, yes, because everything is much too repetitive.

I spend as much time as possible reading, but it never seems like enough. I have an electric page-turner now, so I can read much more in an allotted time. It is an immense improvement not to be dependent upon trying to catch someone's attention to turn the page, meanwhile losing my train of thought and being unable to turn back. Also my time for reading seems to come when my helper is cooking and finds it necessary to wash and dry her hands before touching the book. It's quite impossible to read if I have only a little time. Just getting set up to read takes a good while, so it's difficult to have an unplanned reading session. Once I get set up to a book I'd better plan on staying there for a while. I read a lot of Reader's Digest condensed books. This gives me a smattering of a variety of books. Once the book is set up in the electric page-turner, I'd better not skip around but go straight through it, or a good amount of time can be wasted in fiddling with the gadget.

My favorite time of the day is after all of the therapy and nursing care has been completed and I'm free to direct the household work. Before I took over this task, I was happiest when pounding on the typewriter to have a means of expression. I've always paid a great deal of attention to detail. Perhaps I've been almost too sensitive to small things, which other people might consider unimportant. My attention to detail is now even greater. I've noticed that people will say one word and think another. You can tell from the context that they don't mean what they have said. This used to drive me wild, and I would try to find out if they meant what they said. Then I found out they didn't remember precisely what they had said, so the best thing is to assume they said what fits into their sentence.

Intonation and intent cause me trouble. I think I get some instruction for a child all straightened out with the nurse for her to relay the message. I do this through the nurse whenever I have a sentence that can have its meaning changed when not completed. The children tend to get excited before they find out if I have finished. My own words often scare me when the intonation that was intended has been changed.

It's nearly impossible for me to do any teasing. I can have that intent, but by the time it's translated it sounds serious. I feel a terrible frustration because the translator thinks I'm serious and the teasing has missed its opportunity anyway. After being that frustrated it's difficult to tease, so the whole mood is lost forever.

The most positive result of my situation is perhaps that I'm forced to let the children do things that I might otherwise consider much too difficult for them. I find they can handle much more than I might have let them try, and they are more mature for having accomplished a

difficult task.

What keeps me from losing all signs of sanity when I feel my employee translator has overstepped her bounds? Why does anyone continue to assume the responsibility for caring for me and four very active children? Familiarity seems to be a big factor in the answer to both questions. I now know it's not impossible to learn my idiosyncrasies and live with them. My relationship with each of a number of nurses advanced to a comfortable position, but I've gone through many trials and tribulations to get this far. Familiarity and security must figure heavily in any employee's reasons for putting up with us; it helps to be crazy, too.

APPENDIX

DREAMS in a COMA

Chronologically, these dreams belong at the beginning of MY NEW LIFE, but to understand the struggling efforts of my brain-damaged mind to regain a grasp on reality, it is necessary to follow the threads of consciousness along which my dreams groped - the injury, the hospital environment, my family background, and also my personality.

I realize now that my experiences during the first weeks after the operation were mostly dreams, but they were terribly real at the time. Even when, more than a year later, I came to write of them they remained vivid in my memory. A number of themes kept recurring, such as breathing trouble, hospitals, surgery, classical music and nuns. A few days after my operation a curved metal tube was inserted from the front of my neck into my windpipe to help me breath. It is called a tracheotomy tube, or “trake” for short. The association with hospitals and surgery is obvious. The classical music probably comes from the tape recorder that Vic played for his own entertainment while he stayed with me in the hospital room. The hospital in Oregon was Catholic and staffed partly by nuns.

The first thing I remember is that I seemed to be in a Navy hospital, and we had to line up and dive into the water for our operations. We seemed to be tumbling over and over in the water and were channeled off according to the type of operation while we were swimming under water. I was laid outdoors on a cement slab for the operation. The operation had to be repeated, because something was wrong the first time. So there I was, diving and tumbling again against my will. After the operations, I found Kenny and Larry sewed to my sides. The first time I could almost talk, but the second time I could not. I couldn't seem to stay awake.

The next thing I remember is that there seemed to be a sort of conference and I was moved to a private room.⁸ I kept trying to tell someone that I wanted help to walk to the bathroom and wanted a drink of water, but no one understood me. My ankles seemed to be tied together and I was kicking my feet back and forth very fast. Every once in a while the doctor would look at my feet and laugh. No one gave me water but they kept shoving flowers at me, so I tried to drink the water from the flowers, but they were always just out of reach. I just became thirstier and angrier. I tried everything I could think of to get water with no success.

Then my whole family arrived and passed by my bed as if I were in a coffin. Even Dad and Ethel were there⁹, and it didn't seem strange to them that Mother and Bill were married. They came every day and sat and ate snacks, which they brought, but wouldn't let me have any. Vic wouldn't let anyone in my room after that. After much protest from me he let in only Mother, Bill and Audrey¹⁰. My sister Muriel, as usual, couldn't sit still and started working in

⁸ I was actually moved to a private room a few days after my operation.

⁹ My father and Ethel, the former wife of my stepfather, had been dead for a number of years. My mother and Bill, my stepfather, did visit during the third week after the operation.

¹⁰ Audrey is my sister's (Muriel's) mother-in-law. She visited during the fourth week. Audrey's name wasn't

the kitchen and scrubbed every nook and cranny. She wore a nurse's uniform and tried to sneak into my room, but Vic still didn't let her in. After that, all my younger friends did the same, working in the kitchen and trying to see me. Even Mother dressed up in a nurse's uniform and got in on the pretense of taking my blood pressure, which she was constantly doing, but it hurt like everything.

My doctor was a bone specialist, but I dreamed that he also liked psychiatry and invited us to dinner.¹¹ He seemed convinced that I needed psychiatric treatment. When I took off my coat, I was dressed in a very short show-type skirt. It shocked me so much that they put me to bed with all the doctor's seven children.

After dinner, both for entertainment and because the doctor dabbled in psychiatry, he invited us into his back yard, where he had a trick train that he used to play games on people and thereby find out about their true characters. He liked to choose patients, and tonight I was his subject. For some reason I had to have help getting on the train, so Vic shoved me on without embarrassment. I also needed help to get into the train chair, so Vic pushed me in. The game was very confusing to me but seemed to be clear to everyone else. The game had something to do with passing rings on a wire overhead. Questions were asked by the doctor and answers appeared to depend on how many rings you had left in your hand after the question. The doctor's servant¹² seemed to control the questions according to a script and if you gave a wrong answer she would give you a shot in your mouth of something nauseating. She got very mad when I didn't vomit, and with the help of my family fed me dead rats and sour garbage and made the train go past an unclean hotel window. I still couldn't vomit. My family seemed to help in the train kitchen, and laughed and talked, too.

I wouldn't get up either, so the doctor called out "end of the line" and dumped my whole chair out the window of the train. Vic jumped out after me and we landed in a bunch of babies of different nationalities, which they told us were ours to take care of because I was the last one off the train.

For days I seemed to wake up to a nurse slapping my arms as she held them up in the air. This seemed to be her idea of giving me a bath. When she came on it was a sign that Vic was leaving.¹³ I tried to talk to him, but he just sat by the window, read and ignored what I said. I became very angry because I got no answer. I was especially angry because he seemed to talk to all the young, pretty nurses and be nice to all the older ones, but he wouldn't even answer me. My favorite nurse, Connie, seemed to disappear, except once when she had a conversation about physics problems with Vic and was concerned about his social life¹⁴. He helped her with her physics (which seemed to have something to do with studying for her R.N. - she was an L.V.N.)

mentioned during the conversation. On checking after the visit Vic found out that I could blink my eyelids on her name. This recognition was taken as a sign of real improvement. Muriel was not there.

¹¹ Vic did have dinner once with the doctor and his family of seven children. I don't know where the psychiatry came from.

¹² No servant was ever mentioned.

¹³ Vic left the hospital each evening at about 10p.m. and returned at about 9a.m. I got a bed bath early each morning just before he arrived.

¹⁴ Connie was my favorite nurse before the operation. I had discussed her coming to the University of San Diego (Catholic). Vic did go bowling one evening by himself, but he never discussed physics or social life with Connie.

and told her he had been bowling. Later I seemed to see her at the Catholic University in San Diego. Vic was taking me to many different hospitals, even an animal hospital, but wherever I went I couldn't get away from the doctor with the clicking heels who scratched and hurt my feet.¹⁵ In the animal hospital, I was put into a horse's bed. I couldn't get away from my Mother either. She was there to take my blood pressure, which seemed like a dog sniffing. At one of the hospitals there was a small yacht just outside my window. I was promised to be given this yacht and taken away in it if I would get aboard, but try as I might I couldn't.

I dreamed I was watched one night by all the doctor's psychology students with Vic and the doctor. One nurse was simulating headlights coming toward me and everyone else was taking notes, except Vic and the doctor, who were hiding. This made me very angry. Every time the headlights came toward me, all the students would poise their notebooks. I wouldn't budge, until finally the doctor said, "This has gone far enough. I'm going home to my pregnant wife and seven children whom I never get to see." After that, they made Kenny and Larry jump on my back and I was to shake them off. I couldn't do it; they were very heavy. This all seems very funny now but was horrible at the time, and I couldn't understand why it was happening to me.

I seemed to be taken to many different nurses' apartments, where they had parties and promised me some soda of any kind I wanted if I would wake up. But I couldn't do it. Muriel and Paul¹⁶ were always involved with the refreshments at these parties, and I was always laid out on a couch. I was promised a boat at one of these large parties given on a boat belonging to Muriel and Tac¹⁷, if I would blow pins out of my cheeks and break a soda bottle over the doctor when he came in. Vic spent a long time teaching me to sound like a boat and blow pins at the same time. I tried to escape with Vic in this boat but I couldn't get aboard and no one would help me. I finally got dumped on, only to discover that it was in a channel that needed dredging. It wouldn't lead me home but had a dead end. There was even a cable attached to the boat that kept pulling me back. Bill also tried, unsuccessfully, to pull me home in the boat by attaching the cable to his motorcycle.¹⁸

We found out that the cable attached to the boat and the motorcycle picked up a radio station that played the same music over and over. The disk jockey on this station was supposed to be immortal and he never slept. Actually, the disk jockey was a lot of sisters who took turns doing the work, and traded off when no one was watching.

Every once in a while Vic would take off and fly to a snowy place, like Superman with some special cape attached to his shoulders. At first, he asked me to go with him, but after one trip I had sores on my shoulders¹⁹ from the cape and Vic was very concerned. As much as I wanted to, I couldn't fly with him anymore, but Vic was committed and had to go anyway. He

¹⁵ My doctor had metal plates in the heels of his shoes. He regularly performed a Babinski test, in which he checked the reflex reaction by scratching the soles of my feet.

¹⁶ Paul is Muriel's husband.

¹⁷ Another Muriel, married to Tac. This Muriel is my step-sister.

¹⁸ Bill, my step-father, used to be a motorcycle rider.

¹⁹ Possibly a reference to the bedsores on my shoulders.

would land in the deep snow and never break any bones, although the people who helped him land always-needed first aid. They always recovered and had a party to warm up. He always seemed to land near a house that was well stocked with cokes. He would have a couple and then take off for Albuquerque just in split-second time to be in a performance with his Mother and sister.²⁰ They performed a special act for people who had been hurt and had to wear a special kind of cape to breathe. In this particular theater, the people could breathe without watching their capes to make sure they were closed.

Vic's family did some kind of an act to classical music on skates and with dogs. When one dog died his offspring would take his place. Vic's father was very proud of the family and didn't want anything to change. In his younger days he had been part of the act and was very disapproving of any attentions that Vic and his sister gave to anyone else.

The one time I went along I had to wear one of those capes to breathe and had to sit and wait for hours while whatever was in my cape to make me breathe almost gave out. I got very sore and cramped waiting. My mother and my younger sister, Dot, seemed to be there also and helped with the dogs and costumes. They knew all about the capes and gave me one that Dot had used.

There was a funeral procession for one of the dogs and they played operatic music, the same music that was played in the act. I had to wait in a small, cramped entryway with my cape on. The music seemed to go on forever. Just as my air was about to give out, Vic came rushing in, but the whole staff also came rushing to him to get him ready for a performance. Finally, they were through with him and renewed my air. Upstairs in the theater Dot was having some sort of duel with one of the lady performers. Dot seemed to know the correct combination of squares to step on to win.

Out in the alley my Dad and Bill were trying to revive me from where I had been dumped. With the smell of whiskey and stale tobacco, I finally vomited, which was what the doctor was trying to get me to do in his fake train. Later, Vic and I were told by his father that one of the dogs had pups and produced Vic, and when he was small his head was like the mother dog.

Then I seemed to see Vic trying to cross a snowy ravine between Albuquerque and California. Muriel was there, too; she had three arms and the middle one was flat. They were all made of cloth and Vic was teaching Muriel to use the two good ones. It was a terrible struggle. There were animals with broken legs too.

This troupe traveled from place to place. One time when I was with them they ended up in a small town with no hotel, so we had to spend the night in what turned out to be Connie's house. It was the filthiest and oldest run-down place I had ever seen. This was also Connie's laboratory for biological experiments for her nursing career. I was laid on a filthy bed and spread with a blanket that the dust flew from. A fuse blew out and no one could find another one. There were mice and little snakes and bugs crawling all over me.

²⁰ Vic's mother was dead, and he has no sisters.

I dreamed I was taken to the X-ray office many times. One of the times I was carried there it was because I was positive a piece of metal from something the hospital had inserted to help me breathe was stuck in my throat and if I moved it would gag me. The doctor insisted there was nothing stuck and said, "Has she ever had a trake? She has one now." I could hear my Mother say, "She never had trake trouble before."

Then next I was back in San Diego. There was a crazy hotel, where I was taken, that could instantly be turned into a concealed operating room. This was where I woke up once with the doctor pulling many little bones, like fish bones, from my throat~

In one dream a nurse was shaking me and asking me why I didn't get up after my operation, that people today were weak and spineless after an operation. Even the doctor and my sister Muriel couldn't understand why I was so lazy. So I became angry and decided to show them I wasn't weak and lazy. I was sent to the kitchen to scrub it before breakfast. I was very tired and lay down on the counter, but they wanted me to turn over and get up. They told me I was lucky I didn't have to put on parts of my body like most people did when they got dressed every morning.

One nurse was dunked in the water (suddenly I was on a hospital ship) before she got all the parts of her body on and Paul was called on to pick her up out of the water. He supervised this by a Navy telephone system. Paul seemed to be the captain of the ship and was back from retirement on a volunteer basis. Muriel was a Navy nurse, as was Georgia²¹, all there as volunteers because I was a patient there. Georgia also put on parts of her body when she got dressed up. When she was dressed up she was much heavier than usual. She didn't always put on all the layers of her body and that is why she was so skinny normally, but she looked very nice when all the layers were on.

There was a Navy system for everything over a wire and everyone understood it except me. Vic tried to teach it to me but had no luck. Even the dependents could come aboard and feed hungry children or have them tested for glasses or anything. It made me very angry that babies could catch on to the eating system and I could not. Beverly's²² dog missed the system of eating for a while, and Bill had to drive to my house and leave a big bag of dog food so the dog would not eat up the kittens. He was very angry that he had to drive so far. Vic and Georgia decided to take me out for the evening, so they took me to a place where I had to have a cape to breathe. I felt very proud to be going somewhere.

I dreamed that the children and I were vivisectioned and they gave us a special room in the hospital. There were movie cameras there from San Diego waiting to take pictures. Part of Karen didn't survive and they tried to patch her up with a red stick and a rag doll. They told me she was too small. I was left unfinished in a tank for a long time because the hospital was very busy. While I was there Vic and Paul were ambulance helpers. I was promised a series of swimming ponds in stair steps and one was to be filled with lemonade, one with water, etc., until the fifth and last was to have muddy water in it.

²¹ Georgia is a particularly close friend in San Diego.

²² Beverly is my other stepsister.

We now had twice as many children (almost) as usual so all these pools were very useful. Somehow it seemed that when you agreed to be vivisectioned it revealed your true heritage. We certainly confused the hospital staff with our various backgrounds.²³ Vic seemed also to take up flying to keep busy. This helped the hospital, because he flew patients and supplies. One time he seemed to fly me up to a place where you waited to get into heaven and found some wings that still moved and put them on me and made me keep going, and eventually flew me back to the hospital.

Every night Vic and Bill would disappear, telling me that they had to do turning of all patients. It was a very painful job and required two men and a nurse, and I dreaded this time of day. One time I went along. To turn the patients you put them on a circular metal frame and turned a crank which made the patients very mixed up on the inside of their bodies.

One time I seemed to be driving a new Plymouth and came upon an open field where a huge butterfly was overhead. Other cars were chasing it, so I joined in. It seemed to be a very popular sport. If a car touched the big butterfly it came down like a popped balloon and flew again when repaired. There were all kinds of different bugs that flew along and tried to touch the butterfly also. My Plymouth seemed to be radioed to a wristwatch on my arm. Somehow I drove the car by the armband. I could drive the car over rough terrain, close to other cars, pop the butterfly and never touch another car. After the butterfly was popped, some men rushed up and moved the refreshment stand; others repaired the butterfly and fed the other bugs.

Then in another dream I was driving the Plymouth by the radio on my wristband in a funeral procession for the President of the United States (which one did not bother me). Music was playing and never ended and I couldn't stop crying. I was trying to get people to give money to a useful project as a monument to the President. Part of the project turned out to be a library that went on and on and was never finished. Then there seemed to be a great secrecy about who was to be the new President, who turned out to be Vic. I cried some more because I couldn't go with him; don't ask me why.

In another dream I was put into a round tank at a Navy Hospital and the tank was put under water and I was psychoanalyzed to classical music: first very high-pitched music, then down to very low music. They appeared satisfied after they got down to the very low music. The music was all laid out in a certain pattern. Before you entered the tank, they collected all your personal belongings. My sister Muriel was also put into this tank but she came out very quickly, while I stayed a very long time.

I dreamed that Ethel and Bill bought a huge motel, restaurant, maternity hospital, and bowling alley. Girls would have babies by birds and other strange animals and go to this maternity hospital to have their babies. They had to be turned a certain way after the birth for a few days and every one automatically knew how, except me. I was one of those to have a baby by a very pretty bird. Vic would come and turn me and then go off to the bowling alley. After a few days the bird flew away and Vic tried to get me out of there, but we couldn't find the way. I was stuck full of pins and had to have a certain kind of metal to remove them, but I seemed to keep tumbling over and over on the pins. The pins finally were removed at the bottom of a toboggan-like tunnel in the multi-story building.

²³ Our four children are adopted.

Then I was tied to a carriage and hauled over rocky ground, while I yelled, “Why won’t you let me go home?” The carriage belonged to the hotel and was driven by Bill. Beverly was there, looking for a new husband. She was very haughty and stuck-up. She and Muriel Joyce seemed to know all about the family that played the music constantly. The nuns’ house was only a few blocks away and one nun used to frequent the bowling alley after her early morning prayers. She had apparently met Vic there and told him about the house where she lived. It once had been a movie set and had roads that went around and up like a parking lot inside the huge building that was their house.

Vic seemed to use these roads to drive me around and kept setting a fire in my trake. He said this was to prove to me that I didn’t need it to breathe, but I thought he was very delighted because I was the brunt of a combination practical joke and experiment. I couldn’t fight him and all the nuns that were holding me down. My feet were still kicking furiously so one of the meaner nuns took me and shot my feet full of pins.

The nuns seemed to have a remarkable ability to piece things together out of twigs and old leaves and other odd things. They set about putting me together but it took many years to find the correct parts. In the meantime, my sister Muriel was telling me to “cut the ties, the things that were really mine would come back to me in time.” So I stayed with the nuns for a year while they patched me up. I thought they would never find the correct parts, and just too soon I did cut the ties. I remember that the second story of the nun’s house was not connected and to get from one part to another you had to go to the first floor.

The nuns also had a great talent for stringing these leaves and twigs up from low to high places to make very high-pitched classical music that could not be duplicated. Vic bought one for his Mother and one for his aunt, but first he strung them up in a moving train for some research. He found that the train would go without fuel if he put on the right haunting tune. I had to be very still for this to happen. Vic would get up and stand on me to show how still I was. It seemed to me that he was showing off and I was very angry. But I couldn’t push him off and between the music and cutting the ties and having to be very still I cried and couldn’t stop.

I dreamed we lived in a house on top of a row of houses and there were many dogs fenced up in the back. One of these beautiful dogs was hurt and we were trying to repair his leg. We took the animal to a hospital where we met Alice Dobyne²⁴ with a small dog that she was planning to show again, and she wanted him in tip-top condition. We seemed to be in a long line and Alice seemed to zip in and out.

In another dream we were driving to Tijuana with the Dobyne’s. We found John to be a very wild driver. The car fairly flew over very bad, crowded roads without hitting anything. Both our families had kittens with us. We seemed to hand one out of the window to each person who tried to sell us something. While we were there, John traded in his car, because he insisted it was cheaper. Alice bought a chicken and some strawberries and invited us for dinner, and bought some material that was supposed to be a very good buy, and insisted she was going to make certain articles for Kathy (her daughter), herself and me. They were building new roads

²⁴ John and Alice Dobyne are friends in San Diego.

and traffic was even more congested than usual with road equipment running all over the place. John got into a race with a person who had wanted to buy exactly what Alice had bought. Chickens, strawberries, material, and kittens all got mixed up in the fight. Poor Alice, all her good buys turned out to be very expensive. But she still insisted on making sheaths instead of full-skirted garments.

I dreamed before the flight to San Diego that I had to have another operation. It was to be aboard a large plane that had many rooms. The biggest part of the plane was the operating room and there was very limited space for the crew (sleeping arrangements) and patients. I was on a couch with a pole up the middle attached to both floor and ceiling. I wanted Vic to lie down too. He looked very tired. But he, as usual, was the busiest person on the plane and had no time to wait for me to get my message across.

The next morning I was to go to the operating room, only I had a hard time finding it. Instead of an operating table, there was a net stretched between poles. I was put in a certain position on the net: everything had to be just perfect. After the operation, they put something very uncomfortable on my neck. They took all the spare parts of bodies and put them in the hold of the plane and mixed them all together and tried to make people out of them. But they always had parts left over and they would dump them in the ocean.

Navy officers aboard a ship would dive for the parts and bring them home to their wives as collector's items, preserved by the salt water of the ocean. The ship's captain always had the most precious and unusual possession. All the wives of the officers were after it and when they got it their husbands became captain. The men could also dive for the unusual possessions. The men who dived to the left side to find unusual possessions found it much easier to find what they were looking for. For a long time Gene Regan²⁵ was captain and Arlene kept their unusual possessions up high but on display. Gene also had his house fixed so that only certain people and dogs would cross a certain line into his house: only extremely clean people and dogs.

I dreamed that Vic thought this was a golden opportunity to perform an experiment on me. He and the doctor collaborated to tie the cords or muscles and left a tie hanging out to see if I could find the tie and pull it to loosen the muscles.

I was taken to a home in Mexico because there were nurses there that we had not used. I was left with an unknown Spanish-speaking nurse who didn't know what she was doing. Each weekend Vic would come, but he didn't stay long, because he made a point of saying that he had to be on time for dinner with Muriel. This only served to infuriate me more, because while he always would call to say he was coming, the time was not predictable and always later than I was told, even though he made such a big issue of being on time elsewhere. This Spanish nurse would have the parts of my body all mixed up and very uncomfortable when she turned me. But there was nothing to do but put up with her all week. She was stronger than I was and I prayed that she wouldn't damage my body with some of her bumbling mistakes.

Muriel and I found ourselves captives of people who were teaching some blind people to

²⁵ Gene and Arlene Regan are friends in San Diego. Arlene had, for a long time, periods of severe discomfort from a brain tumor.

ride horses and to impersonate another troop of riders. When they found out we could see they kept it very dark. Muriel figured out a system where the blind could see but didn't let our captors know. They thought the blind people were learning very quickly by feel.

Soon they were ready to try out in front of other people, so they were taken to the nuns, who made all the beautiful music with leaves and twigs, and were pronounced trained. During their first show the troupe whom they were impersonating traded places with them and set them free. This was a very good thing, because there was a terrible difference in their style of riding and they would have been prisoners much longer once their captors realized it.

In one dream evolution was being shown as the survival of the fittest by insects. Each small insect that was lucky enough to be hidden was not consumed by the next larger insect. If a small insect was married to a large insect, it too was protected. I was one of the bugs that was trampled and consumed and I was telling everyone that I was protected as long as my father was alive but when he died I was no longer under protection. And yet, my father had come back from being dead in my earlier dreams.

In another dream, I was in the bad part of Los Angeles and Vic was trying to get me to roll down the back of a couch that was in a store with a big glass window. There were many nurses all over the place, all saying this was the last time they were going to come. They had such short notice and they had something else planned, but they came this time because they had been told that so many had refused. I finally rolled down the couch after a nudge from a strange person and ended up with two nurses reluctantly trying to get me back on the couch.

I had a split back that they wouldn't piece together. The only thing they would do was call my doctor in Oregon and see if he would come and fit my back together. It was broken in stair steps. Finally everyone left except Vic, who was hiding.

There was a ruckus in the next building and the street was swarming with police so we turned out the lights and were very quiet in our building. The police drove by but didn't come in. Much later the doctor tried to find me, but couldn't because it was so dark and quiet. I tried to call out to him, but a hand came out of the dark and stopped me, because it was afraid the police would hear me. Early in the morning we got into a car and drove silently away.

Before the flight to San Diego I seemed to be very busy somewhere else, so Muriel took a trip for me. It seemed that Vic took her for a drive in the country and came upon a place that looked like a large farm, but turned out to be a place where a contest was held each year to see who could thread a cookie-stamping machine. This seemed to be a very difficult task. You had to get yourself into some cramped positions. Alice Dobyne did it very easily each year.

There was also a competition to see who could come down a heavily wooded area and visit every bathroom on the way. This competition was won each year by a nun. After a bathroom was visited by the nuns, the bathroom would disappear.

Also before the flight I had a terrible dream about miniaturization. There existed a race of people nearby that were permanently very small. Two of these small people were stuck on a

ledge with a bridge connecting them to the land where the other small people lived. The people were so small that the bridge was made from a piece of very narrow wire. There were no cars in this town and it was very far to walk, so Vic was the logical candidate to rescue them. Of course, it never entered my mind that a big person could just reach over and get the little people. I couldn't go with Vic to rescue these people but I could see the wire bridge. It was very painful to me to watch the tiny car go over the wire bridge. I had the feeling that it would fall off the wire at any moment. At last the car went both ways across the bridge and was on solid ground again.

One of my dreams before the flight was about having to learn to fly an airplane before I could leave the hospital. So we were forced into these unusual airplanes and made to learn to fly against our will.

In one dream I waited for many weeks in a cramped position in a little rowboat with pins sticking in me, waiting for some water skiers who could fly on their skis made of glass. They were to come from several foreign countries. I didn't know what I was waiting for, but knew it was to be something spectacular. Vic had received information that they were coming, but he didn't know when. He put me in this boat to wait for them, so I could report it to him before anyone else found out. These people had beautiful well-trained bodies but once they landed wrong they were finished in this business. Eventually we bought a house by the ocean where I could watch them from the patio. After a while these people seemed to arrive one at a time, instead of in groups, and we put them up temporarily at the beach house.

One of the people landed on dry land outside a hospital. A special nurse happened to be outside at the time and she caught her with precision timing. This beautiful well-trained body was saved only because the nurse was outside the hospital at the right time.

In one of my dreams I seemed to be perfectly normal except that I was blind. It seemed to be necessary for me to learn to take care of myself without the aid of a guide dog. It was a very painful process, because I had to learn to cross a busy street. For some reason I had no choice.

Throughout these nightmares, I remember snatches of events that I now know really happened.

I remember a nurse slapping me and telling me to wake up. I remember Vic being on the telephone an unusual amount, even for him. I remember him saying that a friend was going to take the children home. I remember him telling everyone how fortunate he was that his sister-in-law had offered to quit her job and take care of the children. I couldn't understand the need. Why should he want anyone instead of me to take care of them? I remember being quite angry about this and even angrier when he seemed to ignore what I thought I was saying.

I remember Vic seeming to be very friendly with the doctor with the clicking heels who always scratched very hard on the bottom of my feet (trying to get a reflex). I couldn't understand why he would let this doctor deliberately hurt me and then be pleasant to him.

I remember being very thirsty and vowing that I would forever after always keep my refrigerator filled with lemonade and offer it to everyone, including repairmen. I couldn't understand why the nurses and nuns would bring in a tray of food and offer it to Vic when I was so terribly hungry. It seemed cruel to me for them to be so concerned about his stomach when mine was so empty. I heard the sound of trays being passed, but the food passed me by and went to Vic. After this happened many times, I despaired of ever feeling comfortable again.

But suddenly I felt my stomach filling up and heard Vic saying, "It looks like she likes that." I heard the doctor giving Vic books to read and I wondered why he was studying so much when he was supposed to be on a vacation. I got very hurt when I thought I was talking to him, but he ignored me and continued reading. I could hear Vic talking about having his tape recorder sent up here.

I remember not wanting to be turned on my sides. It was very painful with all my body weight on my shoulder and the legs feeling as if they were under heavy logs. But I was turned nevertheless. I suppose they gathered the fact that I didn't like to be turned, since I put up quite a fuss when I was on my side. I remember being told they had to do it whether I liked it or not. Being on my back was the best of the three positions, but even this was very uncomfortable.

It felt as if they were trying to even up my body by putting little gadgets under me that looked like little flower holders with needle-like prongs sticking up. I suppose that could have been the bedsores that had developed since surgery. I don't remember the sores as such, but do remember someone always running around looking for a sunlamp. I couldn't understand why they were so interested in me having a tan.

It has been reported to me that during the month or so after surgery I spent nearly 24 hours a day crying. It nearly drove everyone crazy, but was an indication that I could make some sound. Even now, I can make much more sound when I am exasperated or angry. But as my speech therapist says, "You can't go around being angry all the time."

I remember much of the crying. Most of it stemmed from the frustration of trying everything I could think of to talk and still not even having anyone come close to understanding what I thought I had conveyed. Some of it was from the pain I got from being left in one position for longer than I could stand and some of it was the realization that I couldn't take care of myself and my family.

I must have been in the last stages of the coma when I heard Vic discussing how he had rearranged the house to accommodate an extra person. I thought I was giving my views on how this could be accomplished and was being thoroughly ignored. This brought on quite a crying jag and sparked a dream, where I thought I was taking sewing-type tucks in the wall of the house and creating another room and not converting our dining room into a bedroom.

Later on in this dream I saw a housekeeper ruling the roost like a queen. I was placed on a large, very hard table in the kitchen, covered with many sheets, and left while many nurses came and went. It was like a continuous succession of strange people in white uniforms parading through my house. Somehow the tucks in the house put a part of the living room up

two steps from the rest of the house. When visitors came I was on display two steps above everyone.

I felt like Humpty Dumpty after he fell off the wall, and the visitors were all the King's Men. Also, in this dream, there was a large machine which was like the wringer on an old-fashioned washing machine. All my bad thoughts were put in this contraption as black pieces of cloth and came out as good thoughts represented by pieces of white cloth.



Cover designed by Georgia and Bob Partridge