

Halona's Story:
Living as a person with a spinal cord injury
Interpreted by Jim Skouge (as told by Halona Farden)

The Accident

A week before I was to begin my senior year at Kamehameha School, I went over to Maui to visit my brother who was working in one of the big hotels along the Kaanapali coast. He asked me if I'd pedal back to his apartment to pick up his car, so that the two of us could go out to dinner when his shift ended. I hopped on my bike and took off. For whatever reason, as I was passing one of the big golf courses, I decided to take a short-cut and pedal across it. The grass was cut short. It was easy pedaling. Fun. Speed. I came over the crest of a little hill, picked up speed, and in an instant found myself flying headfirst over the handlebars and lying face down in a sand trap. Everything was too fast to comprehend. My entire body was tingling. I could not move. I remember trying to cry for help. A Japanese tourist found me. Hours later I arrived at Straub Hospital in Honolulu. My dad paid for six seats on the airplane in order to make room for me.

Childhood Days

I guess you could say I had always been a "happy go lucky" kind of kid. I was the middle child, with an older brother and a younger sister. We played outside, allot. Most especially at the beach - surfing and fishing. My parents believed strongly in self-reliance. Even when we were very little, we did all kinds of chores - cooking, laundry, cleaning. And we had jobs, whether it be delivering newspapers or selling mangos on a street corner. We learned that money didn't grow on trees.

My parents separated when I was in the second grade. We kids appreciated how our parents sat us down and explained that the divorce was not our fault, and that we would always be loved by both parents. We kids lived with mom, but we always stayed connected with our father.

Although I was a "B" or "C" kind of student, I was the kind of kid who was always testing himself. For example, if mom asked me to run to the store, I ran -- timing myself to see if I could break a record. I'd return home, groceries in hand, huffing and puffing. I loved challenges.

My big brother attended Kamehameha School, and I wanted to follow in his footsteps. I looked like a haole kid - red hair and white, freckled skin... but I was Hawaiian in heart, soul and ethnicity. Oh, how I wanted to go to Kamehameha! I applied in 7th grade, 8th and 9th - but was always wait-listed and turned-down. By the beginning of 10th grade I was pretty much resolved that my dream wouldn't happen. Just a day before the school year was to begin for my 10th grade, the phone rang with the news that there was one open slot at Kamehameha and I could have it. I was overjoyed.

My first few months at my new school were not particularly happy. I didn't have any friends. It was tough coming to a new school in the 10th grade, having missed freshman year, when so many friendships get cemented. I think it was my first day, when I walked into the cafeteria, got my tray of food, and looked all around, seeing the tables full of kids talking and laughing. Anyplace I might sit felt like an intrusion on their space. I just emptied my tray into the trash and walked outside.

I tried out for the water polo team, and made it. That's what saved me. Thank goodness for sports. My team-mates became my friends. True blue friends who have sustained me to this day.

Getting Strong

I spent 2 months at Straub Hospital getting "stabilized" before being transferred to the Rehabilitation Hospital of the Pacific. I remember my high school friends visiting me at Straub. I lay in bed in traction, telling them I'd be back in school by Christmas. I had no idea of the severity of my injury. I figured the bones in my neck were broken and then when they healed, I'd be well.

Upon arriving at the Rehab, it was clear to me that I had to get strong. And I needed to do it fast. Whatever the physical therapists requested, I complied. I had been hurt really badly and now it was time to do the necessary work to heal. That was all I could focus on - the physical part.

I figured if I didn't have the strength to do anything, then I wouldn't be able to do anything else. I mean, if our bodies aren't healthy enough or, at least, decent enough, then we're likely to be sick and non-productive. It's great to have a good head on your shoulders, but if you're going to be stuck in bed that can be really depressing. So, getting fit became my job at the Rehab.

Determination and Realization

Essentially, I could not move my body at Straub. People bathed me, fed me, brushed my teeth. Shaved me. They did it all. And it was still that way when I was transferred to Rehab. It took several more months at the Rehab before I could move my arm enough to brush my teeth or get a spoon to my mouth. One day they introduced me to the feeding machine. This big, cumbersome thing with a robot arm. I pushed a switch and it spooned-up food from a plate with compartments. Looking back, maybe it was nice to know that I could feed myself, but it was more frustrating than helpful. That was not the way I wanted to live. I had to be able to lift my arm to my mouth.

I remember one day I was in the physical therapy room, sitting on a mat. Propped-up is the better way to put it. We were working on my balance. The therapist would prop me up and I'd fall forward or over to one side. It hit me. "I can't even sit up. I'm hurt really bad." I didn't always tell my family about my feelings. I'm the kind who kept them to

himself. But many nights, after my family had gone home, there were tears on my pillow.

The Rehab Counselor: Bad timing

One day at the Rehab Hospital the staff arranged a meeting for me with a Vocational Rehabilitation Counselor. I wanted to be polite to the gentlemen, after all he had come down to try to help me. I listened as best I could. But by the time the meeting was over, I had the impression that he had my whole education mapped out for me. He wanted me to go to Leeward Community College to become a counselor - and from there to attend university to become a social worker or something similar. He said I'd be good at that. (Looking back, I realize he could not possibly have known what I'd be good at. He didn't know me.) You have to remember, these people have one goal - to make you employable and turn you into a tax payer. I could not appreciate what he was saying. I had one goal, too -- to get strong and return to family and friends. I still had to finish high school.

Kamehameha Homecoming

Soon after arriving at the Rehab I received hundreds of letters and well-wishes from my fellow students. It meant a lot. I had no idea that so many people would think of me and care enough to write. My close friends (true blue buddies) visited me regularly all year long. With the support of the Kamehameha School I was permitted to complete my senior year while I was a patient at the Rehab. I will always be grateful to them for that.

In April of my senior year, two of my friends came by to tell me that I had been selected by the entire school as Homecoming King. I was shocked. "I don't want the award," I said, "you are doing this because you feel sorry for me." My friends couldn't persuade me otherwise.

A couple of days later a large group of athletes descended on me. "Who do you think you are to tell us who we can elect Homecoming King. We voted for you because you deserve it, not because of your injury. We're going to take you to the Homecoming game whether you're dressed for it, or not." With no choice, I agreed.

On the day of the game, all dressed-up, I was wheeled into the stadium. I received a standing ovation. I couldn't believe that so many people liked and cared about me. This was truly my homecoming.

Looking back, my "true blue" high school friends have stuck with me through all these years. I haven't really had time to make many new friends since the accident. I have a circle of friendship anchored in my days at Kamehameha.

Ka Makua Mau Loa Church

I remained at the Rehab Hospital for almost a year. I knew that leaving was not going to be easy. There was just no way that I was going to impose myself into either of my parents' homes. Everyone was working. It would have been way to much to care for me. "What to do? What to do?"

The minister of an Hawaiian Church in downtown Honolulu offered me the opportunity to live in the church. Several people were already living there - paying back their rent by tending the grounds and caring for the buildings. "They could also take care of you," he suggested. I agreed to try it.

I lived at the Ka Makua Mau Loa Church for almost a year. The caretakers were good people who cared about me and were attentive to my needs. I still had my high school girlfriend who also came over to stay with me - although that relationship dissolved as the year went by.

I had a lot of time to think during that year. The minister would talk to me. I spent many hours by myself in the chapel. Friends and family visited. The church provided a spiritual recovery - not to mention my relief that I was not causing more struggle for my family.

It was near the end of that year that my father proposed that I attend the Craig Institute in Colorado. We had heard that it was a wonderful place, and my father was willing to pay for it.

Leeward Community College: Getting back into the groove

During my time at the Ka Makua Mau Loa Church, I began attending Leeward Community College (LCC) - just taking one class, a day or two a week. It was a long ride out there on the Handicab (probably 2 hours or more, round-trip), but I chose LCC because the campus was flat and buildings had elevators. Remember, this was before the ADA - so most of Hawaii's campuses had few accommodations. At that time, LCC was one of the few community colleges to have Disabled Student Services.

I liked it there. The transportation hassles were worth it. I became friends with the other guys on the bus. And I liked the "disability services" (Komo Mai) that were provided. I got to know the Komo Mai staff and felt comfortable with them. They made it so we didn't have to ask strangers for help. They assisted with note-taking. Helped me empty my leg bag. Provided typewriters and testing accommodations. They had people who could push us from one place to another. They had tables right outside their offices where they set us up for lunch. They'd open our backpacks, bring us food from the cafeteria, and such. It was like an extension of the Rehab in a way - a safety net. They were good people. They made us feel welcome. It was "comfortable."

I didn't have a powered wheelchair then. I wouldn't have wanted one even if it had been a choice. Remember, I wanted to get strong. I was at that point where I was propelling

my own wheelchair -- at least on flat ground I could get myself from "point a" to "point b." A point of pride.

I began thinking about an Accounting Major. I had always liked numbers and business. Maybe, just maybe, I could have a professional career.

Craig Institute

I was 19 years old when I left for the Craig Institute in Colorado Springs, Colorado. I had been living for some time at the church, when my Dad heard about the Craig Institute and encouraged me to go. I wanted to, but I was scared at the same time. Colorado seemed so far away. I had never been beyond our Neighbor Islands, and I was comfortable with the people at the Church. I did go, and I guess you could say "I came of age." When I returned to Hawai'i, just 2 months later, I was eager to say goodbye to the Church and get on with independent living.

At Craig I realized that there were many things that I could do, provided I had the tools. I had potential. Granted, I was hurt - and my life would never be the same as before the accident. But, I had possibilities. I met people at Craig, in the same situation as my own, doing things that I hadn't dreamed were possible. It was like, "How did they do that?"

Skiing was one. They were just testing sit-down skis for the "para's." It was eye-opening for me. I'm going, "WHAT?????" And, of course, it was the mainland, where things happen faster than here in Hawai'i. But still it helped me to realize that I had a future. The key was to adapt - to make adaptations and get the right tools.

The people at Craig helped me make "an attitude adjustment." The staff was all young - and most of us "clients" were, too. It was as though youthful attitudes prevailed. One time when we were outside, one of the staff asked me if I wanted to get out of my wheelchair and lie on the grass. Before I could protest, he swooped me out of the chair and layed me gently in the green grass. Blue sky and fluffy white clouds were overhead. "I'll be back for you in a bit. Just enjoy." As I lay there, I realized that I WAS NOT THE WHEELCHAIR. I was a person, unchanged from before the accident. The wheelchair was just a THING... a tool, nothing more...

Another time we were on an outing, when we stopped at a genuine Indian teepee that was the honest-to-God summer home of one of our Craig staff members. I was sitting in my wheelchair outside the canvas opening, talking story and taking everything in, when someone suggested that we go inside. "No need," I said, "I can just look in from here." They wouldn't hear of it. Over laughter and protest, they carried me in and propped me up. We talked and laughed in that tent for over an hour. A time that I will never forget. Wheelchairs are just tools. They do not define us. Thanks for the lift.

It's like we weren't "patients" at Craig. It was more like living in a dorm - complete with parties, beer and girls who weren't in nurses uniforms.

My Powered Wheelchair

While I was at Craig I got my first powered wheelchair. It was purple, fast and road-worthy - totally different from the institutional electric chairs I'd seen in Hawai'i. Before Craig, the only electric chairs I had seen were fragile things with hard rubber tires, bicycle spokes and a limited cruising range of a mile or two on a charge. Nothing that made sense to me, especially since I hated the look of the chest straps that I would have to wear should I choose to drive one. I saw the electric chair as a symbol of giving up my dream to get strong and well.

All of that changed when I met the people at Craig and saw the chairs they were driving. I'll never forget the day one of my new-found friends invited me to join him on an outing to the nearby Mall. He already had his powered chair, and somehow I just couldn't say "no" to the invitation. We borrowed an electric chair for me, and caught a lift on one of the Craig buses down to the mall. After saying "goodbye" to the driver, we became free.

I had forgotten how wonderful it is to go... just to go... to cruise down the aisle of a record store; to run circles and figure-eight's; to race around a parking lot -- just to do it. We went anywhere and everywhere. Cruising. I was sold. Powered mobility was to be my key to freedom. The folks at Craig immediately ordered me a chair.

I returned to Honolulu with the new chair on board. I moved into a "transitional living" program at the Rehab, where I diligently practiced my driving skills. This was before curb cuts, mind you. At first, I wasn't confident about my driving - fearing that I might flip the chair sideways. I practiced and became skilled and stayed accident free (at least until some years later when I should have known better).

Transitional Living

Upon returning from Craig, I spent a year living in a newly instituted "transitional living project" sponsored by the Rehab Hospital. I lived in an "apartment" on the hospital grounds, but the experience this time was entirely different from my 10-month "hospitalization" two years earlier. This time I was there to learn to manage my routines in preparation for a return to community living. I was now 19 years old and beginning to feel responsible for my life.

To begin with I had to assume responsibility for my own body. At Craig they had taught me to use a mirror to examine my skin for red marks or blemishes - the first signs of skin break-down. I learned not to depend on the observations of my attendants. When it came to my skin, they were to report everyday on what they observed and I, in turn, would confirm with a mirror. I had been shown a slide show on "decubitus" - all the various stages of skin break-down (bed sores) and I was determined to be my own best friend.

I think my biggest challenge was to learn to plan ahead and be strategic. The attendant arrives to do his "chore services" and in just a few hours he or she is gone. Then I'm

alone. My challenge was to visualize everything I'd need and to plan for every contingency.

Do I have enough water? Are my books laid out? Is paper handy and what happens when the sheets blow in a gentle breeze? Do I have sharpened pencils? What's my back-up when gravity takes over and things hit the floor? If I'm in bed for the day, will my urine bag accommodate my output? How much should I drink? Is the phone accessible? Where's the remote for the TV? Can I turn-on the fan if the room warms up? How do I handle the afternoon sun that comes blazing through the window?

Beyond everything is GRAVITY. It plays a head trip on quadriplegics.

Remember, I was only 19 years old. Learning to live alone. Not only having to plan every minute detail, but having to communicate and supervise an attendant who might have his or her own ideas about how to run my life.

"Time to grow up, Halona."

Transition into Community

In 1982, I "graduated from the Transitional Living Program and began living on my own in a rental house on the slopes of Diamond Head, near Kapiolani Community College. The house was just right for me. My mother and sister had been living in the house. They moved out to make room for me. The landlord was willing to accept rent subsidies. He understood my situation and was willing to let us make minor modifications to the house. My mother and sister rented a house nearby for themselves.

The front yard was flat, all the way from the sidewalk to the kitchen. Perfect for access. The living room was large. I ended up living and sleeping in there. Other than the living room and the kitchen, the rest of the house was pretty much out of bounds. No matter. My attendants could pick me up and carry me into the bathroom. No need to shower outside.

I was within cruising distance of KCC. So now, weather permitting,* I was no longer dependent on public transportation to get to school. How wonderful to drive to school on my own in my powered chair. I enrolled in 1 to 2 classes per semester, as my health permitted.

My family ties remained close. We had parties at the house and, oftentimes, my cousins and family friends would stay over. We even set-up a ping pong table in the living room. By that time my mother had remarried. Her husband's daughter, Mileka, was then a high school student. Mileka and her friends spent lots of time at the house. Some years later, Mileka and I were to become lifelong partners.

A note on "weather" - rain is hard both on wheelchairs and wheelchair users. It can short-out anything electrical. And it can soak the driver. Both of which can lead to bad outcomes. It takes a long time to repair the chair (during which you do without). And it's tough to be sick. You end up pretty much confined to bed. It's not like I can dry off and change clothes when I get home, unless it's all been arranged beforehand with the attendant.

Managing Attendants

By 1982 when I moved out on my own, I knew my routines. Thank goodness. This was before "Nursing Home Without Walls." so I was completely on my own as far as hiring attendants. I'd run ads in the paper and then interview people, just as any employer, asking for references and all. I tried to treat it like an employer-employee relationship. "Here's what I pay. Here's what I need."

In actuality, it's never as simple as that, however. Attendants cook for you, bathe you, take care of you. The relationships can get confusing. One attendant wanted to try acupuncture on my neck. He was a good cook, but I got suspicious of his motives and let him go. Once I invited a couple to live with me - thinking it would be great to have someone around whenever I might need them. Their lifestyle was different than mine, however and I asked them to leave. It's better for me to have my privacy. I like things certain ways.

Some people with disabilities take advantage of attendants, asking them to do things that are beyond what's fair. And, on the other side, some attendants take advantage, too - eating from the fridge, kicking back to watch TV, acting like a room-mate. A person with a disability can be at the mercy of an attendant. When I'm in the shower, for example, how do I know what the attendant's doing in the other room? A stranger in your house. This may become even more of a factor when you share your home with someone you love. Then the attendant can be an intrusion on your partner's life, too. Now, when I hire an attendant, I have to think of Mileka. It's her home, also.

Low Tech Adaptations for Independence

During my college years, I have lived in several rental houses. With support from my friends, and input from a physical therapist at the Rehab, I learned to make many low tech adaptations to maximize my independence, including kite strings with loops to adjust my blinds and turn-on fans and lights; mouth sticks to change channels; a dog leash to close my door; a wooden handle on my door key so I can use my mouth to lock and unlock; an adapted bed and dycem mitts, so I can lie down and get up independently; a handset grip for my telephone; and hand splints for holding spoons and dowels for eating and typing and such.

We have produced a video on these adaptations, which I encourage you to view. It is entitled "Halona at Home."

College Life

Looking back on it, I spent many, many years going to college - perhaps 15 years. I earned a Bachelor's degree in Business, taking just one or, at most, two courses a semester. And sometimes I missed a semester all together due to illness. I made mistakes along the way. Plenty of them. Many of my course credits, for example, did not transfer to UH Manoa when I transferred there in my junior year. I should have sought better advising, early on. Oh well. I enjoyed most of it. But by the time I graduated in 1996, I was a little burned-out. I still am. It shouldn't have taken so long.

Probably one of the toughest things that I had to learn after my accident was asking people for help. You know, you grow up proud of your independence, valuing your independence, and then you end up in a situation where time and again you need help. It's tough. I remember, early on, it was even difficult for me to ask someone to take notes for me in class - even though they would be paid for it!

Most professors were accommodating to me. If I needed to turn-in a paper late, it was rarely a problem. If I missed classes due to illness, I could make them up. One professor even gave me his lecture notes on disk. I promised to share them with no one. I was so grateful.

I had tutors and note-takers when I needed them, which was wonderful. It's tough to do mathematics when you can't hold a pencil. Typewriters and computers are great for essays, but tough for mathematics and scientific formulas. Even essays, by the way, take lots of time. I was never able to dictate my essays to someone else. I needed to type them out, one letter at a time with dowel in splint. A laborious effort, which often resulted in neck and shoulder pain.

Of the things I dreaded, getting caught in the rain was near the top of the list. Then there was being late to class - sitting in some hallway in front of a closed door; bumping it to get someone's attention, waiting for it to be opened; and then interrupting everyone, as the "quad" wheels-in, searching for a place to park; smiling and trying to act invisible. No fun.

And then there were the dreaded group projects. Some professors just love to have students work in groups. The problem is that most students live differently from me. They like to meet in the evenings, perhaps in a dorm room, or the library or a coffee shop. But I have to be home in the evenings. When my attendant comes to put me to bed, I have to be there. No excuses allowed. Furthermore, students can sleep-in. My day starts between four and five in the morning. It takes hours to get me ready for the day: stretching, bathing, grooming, dressing, eating, buses, etc. No wonder I need my rest at night. One semester I took a music class that started at 8:00 a.m. I had to get up at three o'clock in the morning to make that class. It was a great class, but nobody paid the dues like I did.

Was college worth it? Sure. What would I have if I hadn't gone to college. Would I do it differently the second time around? Most certainly, yes. I would want better advising; voice dictation for my computer; lecture notes in electronic format; and a balance of campus-based and Internet based coursework. My years of going to college taught me my strengths and limitations. Hopefully, this self knowledge will help me now that I am embarking into the world of work.

Fitness and Sports

The highlight of my years at the University of Hawaii was my involvement in wheelchair athletics. Because of the commitment of Dr. Jim Little, a professor of physical education, many wheelchair users became active in weight lifting and all sorts of competitive athletics, including riflery, ping pong, and track and field. Dr. Little created an adaptive gym and staffed it with practicum students who were enrolled in his courses, so that we wheelchair users could access equipment and safely use it. It was wonderful.

I worked out 2 or 3 times a week and returned home with a good feeling of fatigue. I never slept so well as during those years. Just as important, however, was the camaraderie of good friends working out together. Words alone cannot express our appreciation to Dr. Little. Physical fitness and physical disability go hand in hand. This is something that the able-bodied world does not understand. They assume that people with disabilities can't do and don't want to do. Nothing could be further from the truth. Quite simply we need access and support.

In 1991 the University of Hawaii installed a wheelchair lift in the swimming pool. This was a day for celebration. I began swimming on a regular basis. Nothing could have been better for my health. Again, thanks to Dr. Little, we had student attendants who could support us in dressing, drying and transferring. A pool lift, in and of itself, is inaccessible to persons with quadriplegia. We require human supports as well.

A New Job

A year ago, I took my first "real job." I work for PAC MED - a one-of-a-kind "one-stop shop" for assistive technology. Finally, I'm out of the student mold. It's a great first job. My hours are flexible. I don't have to come in first thing in the morning. I can do some of my work at home, and I'm anything but bored. I'm involved in sales and training. And the assistive technology field is something that I know firsthand, through years of experience.

Among other things, I provide training to persons with disabilities to use voice dictation for their computers (specifically, Dragon Dictate and Naturally Speaking). I use the software, myself, for my own productivity, which surely adds to my credibility as an instructor.

PAC MED is a new business. I enjoy participating in the challenge of getting something new off the ground. Along with low technologies for activities of daily living, we

demonstrate and sell a wide range of high technology adaptations for the home, including computer-based environmental control units, accessible bathrooms, kitchens, laundries and the works.

Mileka and I now live in our own dream home in Ewa Beach. We couldn't be happier with our living situation - except, perhaps, for the fact that it requires a long commute back and forth to work. Transportation remains a challenge for us. And the commute can make for a very long day. In the excitement of being employed and wanting to do my best, I have to remind myself to maintain a pace and lifestyle that is healthy for me.

I try to be assertive with my employers - telling them what I need in order to stay healthy. If I have to stay in bed for a day or two, for example, I try to do just that. If it's better that I come to the office for just a half day, I insist on it. I can work at home, as I have both a desktop and a laptop computer. I try not to compare myself to other quadriplegics. Each of us have different levels of stamina and health. Our individuality must be respected. Our health must come first.

As a part of my commitment to community service, I serve on the Board of Independent Living Housing for O'ahu. This provides me the opportunity to support others with disabilities to have quality choices for home and community.

Looking to the Future

Life is uncertain, at best. It's always a little crazy to try to predict the future. Five years ago, for example, I would have never predicted that Mileka and I would have such a beautiful home, or that I would be working in the field of assistive technology.

My hope is that Mileka and I will continue to have children, animals, family and friends to enrich our lives. That's really what it's all about for us. Mileka is the light of my life. My love for her is beyond words.

One day, not too distant, I hope to become a Certified Public Accountant (CPA). I earned that Business Degree - and I do want to take advantage of it. The thought of studying for the exam sometimes seems a bit overwhelming. But I expect one day soon to buckle down and crack the books.

As you may or may not know, persons with disabilities who obtain gainful employment face the risk of losing their government benefits. This is a terrible contradiction which serves as a disincentive for work and independence. We look forward to a future where this becomes resolved.

Transportation continues to be one of our challenges. We would love to acquire our own wheelchair accessible van, with a lift. I've even wondered if perhaps one day I could drive. Although for now we'd be happy just having me on the passenger side.

We'd also like to acquire an environmental control unit which I can access from the bed. I do spend significant time alone at home. That will not change. I'd like an effective way to control lights and fan, window blinds, and perhaps even television and stereo.

I want to get back into swimming. I don't have Dr. Little and his circle of support any more. An accessible pool has just opened, however, right next to my workplace. Perhaps that will give me the opportunity to do what I know is right.

Finally, I'd like to write a book about "do's and don'ts" for quads. I've been through a lot, and I would love to share my experiences. In that light, I look forward to internet dialogues with people around the world who might be reading these stories. So, we face challenges ahead. Don't we all? We're sure grateful for where we've come so far.

Expressions of Gratitude

No story is complete with saying thank you to the people who have made my life possible. Thank you to my parents and family. Thank you to Mileka. To Malu. To my true blue friends who've been loyal throughout these many years. And to Eddie Shon whose unflagging optimism has taught me that life doesn't end when you become a quadriplegic.