



# Colorado Post-Polio Connections

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*Thank you from the Colorado Post-Polio Connections to the following volunteers who have made this newsletter possible: Jeanine Ellison-Fisher, Dr. Marny Eulberg, M.D., Delores Glader, Nancy Hanson of Easter Seals Colorado, Marlene Harmon, Margaret Hinman, Barbara Lundstrom, Margaret Ann McCarthy, Chuck Malone, Barbara Nickelson, Jim Oxley, and Woody Trosper.*

## A STATEMENT ABOUT EXERCISE FOR SURVIVORS OF POLIO

*Advising all polio survivors not to exercise is as irresponsible as advising all polio survivors to exercise.*

Current evidence suggests that exercises are often beneficial for many polio survivors provided that the exercise program is designed for the individual following a thorough assessment and is supervised initially by knowledgeable health professionals. Polio survivors and their health professionals who are knowledgeable about the complete health status of the individual survivor should make the ultimate decision on the advisability of exercise and the protocol of the exercise program.

Clinical research studies support exercise programs that are prescribed and supervised by a professional for many polio survivors, including those with the symptoms of post-polio syndrome. *(References are listed on page 11.)*

Acute paralytic polio can result in permanent muscular weakness when the viral infection leads to death of anterior horn cells (AHCs) in the spinal cord. Recovery from paralysis is thought to be due to the re-sprouting of nerve endings to orphaned muscle fibers creating enlarged motor units. Recovery is also attributed to exercise that facilitates the enlargement of innervated muscle fibers. For example, some polio survivors regained the use of their arms and have walked for years with crutches. Others regained the ability to walk without the aid of braces, crutches, etc., and have continued to walk for decades.

The increased muscle weakness recognized in those with post-polio syndrome is believed to occur from the degeneration of the sprouts of the enlarged motor units. The premature death of some of the AHCs affected by the polio-virus is speculated to also cause new weakness, and some new weakness is caused by disuse, or a decline in activity or exercise. *(Continued on page 3)*

## In my opinion . . .

Over the years, the expert recommendations about exercise for polio survivors have changed. At the onset of polio, weakened muscles were to be strengthened and restored. After a fall in the 1970's, physical therapy was to strengthen the one muscle in my knee that still functioned. Over the years the adage, "use it or lose it," the prevailing wisdom when I first had polio had changed to "conserve it to preserve it." And, I was led to believe that those muscles ravaged by polio could not be rehabilitated.

So, when my primary care doctor suggested that I see a physical therapist so I could regain or improve some muscle strength in my leg, I was skeptical. Yet, over time, my walking had become more labored, and I wanted to improve my balance and my gait. After finding a physical therapist that knew polio and post-polio, I began a three-year journey which has improved my balance, and restored my gait to near that of a person walking "normally" (when I am not too tired and with the help of forearm crutches!!). I have also increased strength in muscles that either have been unused, or misused over the years and, perhaps, some muscles affected by the polio virus.

The journey has been slow, the gains miniscule at times but I have seen progress and I will continue to get physical therapy, my exercise of choice along with my "fair weather" walking routine.

This issue of the Connections explores the literature on exercise for polio survivors, with the current prevailing wisdom being to exercise using good judgement. The two feature articles relate the current thinking on the role of exercise, its benefits, and the guidelines as to how to exercise in order to prevent further harm to those muscles that don't work so well.

"And by the way . . ." is a summary of a survey taken by those attending the Fall Connections educational meeting. It shows how many different ways we can get our exercise.

Another feature that we thought to include in this issue was a listing of accessible, warm water pools in Colorado, thinking that they might provide exercise options for some of you, but confusion about the criteria for a warm water pool and the number of pools made it impossible to provide a comprehensive list that made sense. However, the research on pools has led me to ponder the whole issue of finding the right exercise and exercise resources.

Over the years, I have tried various exercise routines, never sticking with any one for a long period of time. The stationary bike that was to be the answer sat unused for years in my house, until the house was sold. Yoga worked until my favorite instructor quit. Weight training lasted for about six months. I wouldn't walk in my neighborhood because it was "ugly" and didn't drive to a more aesthetic neighborhood. Swimming and water exercises were too stressful, because I was always worried about falling on the wet pool deck. *(Continued on page 9)*

***A special thanks to the Oran V. Siler, Co. and to Easter Seals Colorado for printing and distributing our newsletter.***

## A Statement about Polio . . .

*(Continued from page 1)*

There is agreement that repetitive overuse can cause damage to joints and muscles, but can repeated overuse and excessive physical activity accelerate nerve degeneration or nerve death? This is the crux of the physical activity/exercise debate.

Physical activity is movement occurring during daily activities. Exercise is defined as planned, structured, and repetitive body movement.

Therapeutic exercise is conducted for a health benefit, generally to reduce pain, to increase strength, to increase endurance, and/or to increase the capacity for physical activity.

Polio survivors who over-exercise their muscles experience excessive fatigue that is best understood as depletion of the supply of muscle energy. But, some polio survivors' weakness can be explained by the lack of exercise and physical activity that clearly leads to muscle fiber wasting and cardiovascular deconditioning.

The research supports the fact that many survivors can enhance their optimal health, their range of motion, and their capacity for activity by embarking on a judicious exercise program that is distinct from the typical day-to-day physical activities. These same polio survivors need not fear "killing off" nerve cells, but do need to acknowledge that the deterioration and possible death of some nerve cells may be a part of normal post-polio aging.

Exercise programs should be designed and supervised by physicians, physical therapists, and/or other health care professionals who are familiar with the unique pathophysiology of post-polio syndrome and

**Here is Dr. Marny Eulberg's "quick and dirty" recommendation about exercise for polio survivors:**

"Stop the activity just short of what you know will cause pain, the muscle feeling like 'mush' or won't allow you to do one more repetition/take one more step etc. or you get fasciculations (muscle twitches) in the muscles that are working!"

the risks of excessive exercise. Professionals typically create a custom-tailored individualized exercise program that is supervised for two - four months. During this period, they will monitor an individual's pain, fatigue, and weakness and make adjustments to the protocol, as needed, to determine an exercise program that a polio survivor can follow independent of a professional.

When designing a program, these general principals are followed to achieve specific goals and/or maintenance levels.

- The intensity of the exercise is low to moderate.
- The progression of the exercise is slow, particularly in muscles that have not been exercised for a period of time and/or have obvious chronic weakness from acute poliomyelitis.
- Pacing is incorporated into the detailed program.

*(Continued on page 11)*

*Editor's Note: the following information is an excerpt from Lauro S. Halstead's book Managing Post-Polio, A Guide to Living Well with Post-Polio Syndrome.*

## Managing Exercise

It is well known from muscle physiology that exercise of various types improves both muscle strength and endurance. Following episodes of acute paralytic polio in the past, individuals often went through long periods of exercise training and muscle re-education to regain the strength and muscle mass they had lost. In fact, exercise was frequently viewed as the "cure" for paralytic polio. The belief of many persons was that they could overcome or "beat" polio if they did enough exercises.

When people started getting new weakness many decades later, that same belief was still intact. As a result, many individuals resumed exercising on their own, often with a vengeance, frequently producing additional weakness. Based on these anecdotes and the initial theory that PPS was caused by overburdened motor neurons, it is understandable that most clinicians were cautious about prescribing any form of exercise. Now, more than a decade later, there is considerable evidence that almost everyone can benefit from some form of exercise. For many individuals, this level of exercise may be nothing more strenuous than gentle stretching or various types of yoga. For others, it may be considerably more vigorous and even include aerobic training. With this range of options, it is impossible to prescribe a set of exercises suitable for everyone. Instead, a list follows of general principles and guidelines that can be used by most people with PPS to develop a safe and effective exercise program:

- Individualized and supervised program. Exercise programs should be supervised initially by a physician or physical therapist experienced in neuromuscular diseases, if not polio. All programs should be customized to each person's needs, residual strengths, and symptom patterns. Given these constraints, research studies have shown that some polio survivors (but not all) can improve muscle strength (caused by new muscle hypertrophy and the growth of additional terminal axon sprouts) and enhance cardiovascular endurance with a closely monitored training program. In fact, some studies have reported an increase in strength in muscles both *with and without new weakness*.
- Type of exercise. There are numerous kinds of exercise. Finding the one that is right for each person and each limb often takes trial and error. Usually, it is a good idea to find two or more exercises that can be varied, exercising specific muscles every other day. For example, walking or exercising the lower extremities one day and alternating with an exercise for upper extremities the next day. This program provides a period of rest for each muscle group and variation that keeps the overall exercise program challenging and enjoyable. As a general rule, muscles that have a grade of 3 or less (using the muscle examination scale: 0 = no contraction up to 5 = normal strength) should be protected and not exercised; grade 3+ muscles can be exercised with caution; grade 4 and 4+ muscles can be exercised moderately; and grade 5 muscles can be exercised more vigorously.

*(Continued on the next page)*

- Expect improvement. Exercise should make one feel better physically and psychologically or both. If the activity is not strenuous enough to improve and individual's strength, much less the cardiovascular system (e.g. stretching or yoga exercises), it still should give a psychological lift just to be doing a special activity for oneself on a regular basis.
- Listen to your body. Avoid pain, fatigue, and weakness. These symptoms are signals that your muscles have overworked. A brief period of fatigue and minor muscle pain for 15 minutes to 30 minutes after exercise is usually normal. Symptoms that last longer than 30 minutes to 60 minutes after exercise is usually normal. Symptoms that last longer than 30 minutes to 60 minutes reflect muscle over-work and possible injury. If this occurs, the exercise should be reduced or stopped. *Any exercise that causes additional weakness should be discontinued immediately.*
- Pacing. Pacing has been shown to be safe and effective in increasing strength in some individuals. The intervals of exercising can be as short as two minutes to five minutes alternating with equal intervals of rest. The evidence also shows that secondary symptoms, such as generalized fatigue, can be reduced as individuals become conditioned and are able to perform more work with less expenditure of effort.
- Use your best muscles. Polio is often a focal, asymmetric disease with variable amounts of weakness in different limbs. Exercise the limbs least affected or those completely unaffected by polio, while avoiding the more affected extremities. For instance, if only the legs were affected, then the arms can be used in a fairly strenuous program that includes swimming or using an upper extremity arm bicycle; meanwhile, the legs will usually get adequate exercise in the course of doing daily activities.
- Hydrotherapy. Water therapy was the exercise of choice for many persons during their recovery from the original polio. It is still excellent therapy. Because of the buoyancy of water, it allows people to do things they can't perform on land. For especially weak limbs, inflatable cuffs can be used to float an extremity. For other limbs, water resistance provides a workout that can be fine-tuned to each person's strength. The principal disadvantages of hydrotherapy are that the temperature may not suit one's body and it may be difficult to find pools that have lifts (if needed). Also, the surfaces around pools tend to be slippery and dangerous for anyone with a tendency to fall.
- Warm-up and cool-down. As with other exercise programs, a warm-up followed by gentle stretching should be done to improve flexibility and reduce the possibility of injury. After exercising, a cool-down period should take place. Finally, the type of activity should be one that the participant enjoys to minimize the potential for dropping out because of lack of interest.

## MY FRIEND, SUSAN

*By Barbara Lundstrom*

I met Sue in 1955 at a Catholic singles' party. My friend, Charlie, excused himself to dance with his "girl friend." There on the dance floor I saw a spunky, and very pretty 4'9" lady wearing two shiny braces locked at the knees, balancing on the top of Charlie's size 13 shoes, being twirled across the dance floor with all the grace and charm befitting a ballroom dancer! That was the beginning of our lifelong friendship, with a special common bond — we'd both had polio!

Susan Gonzales was born in 1925 in the small town of Portland near Florence, Colorado. At the age of five, she fell, thinking she had hurt her spine, was very tired, feverish, and wanted to sleep most of the time. She was unable to get out of bed without falling. Her parents took her to Children's Hospital in Pueblo where doctors quarantined her and diagnosed her with polio. Sue's legs were paralyzed, but as she got stronger, she learned to crawl again. Sue was a happy, playful little girl and wanted to go to school. She had no way to go since her brother Dan who often carried her around on his shoulders, would be attending high school in a nearby town. So, Sue secretly begged money from neighbors to buy a wagon. When her father learned of this, he told her to return the money, but her neighbors refused. Sue enthusiastically began the first grade arriving in a new wagon pulled by her friends.

The principal arranged for Shriner's Hospital in Minneapolis to admit Sue. While there, she had two operations on her ankles and received therapy for seven months. In the meantime, her mother became very ill and Sue was called home. Later, she returned to

Minneapolis for more operations on her legs and was fitted with braces and crutches.

Sue's parents both died before her thirteenth birthday, but with the loving care of two older brothers and two younger sisters, she continued her education despite many summers and school weeks spent in Children's Hospital in Pueblo. Sue graduated from high school second in her class. Upon graduating, she won a National Essay contest sponsored by the Elks Club. This money paid for her college education.

Sue received a B.A. degree from Western State College, Gunnison, CO in 1949. While in college, she was Secretary/Treasurer of the Alpha Sigma Alpha Society, President of the Newman Club, President of Phi Omega Phi and Sigma Delta Pi (both are Spanish honorary societies) and a member of the student council. She had a very busy academic and social life.

After college, Sue moved to Denver, intending to teach and be an interpreter of Spanish and French. At that time, the Denver Public Schools (DPS) did not hire the physically handicapped but this did not discourage her. While waiting to hear from the Civil Service regarding a job application, she worked as a proof reader for the Denver Catholic Register and as a court reporter for the City and County of Denver. The Civil Service accepted Sue's application and appointed her to the Air Force Accounting and Finance Center (AFAFC) where she worked for twenty-one years. Sue proved to be a top-quality worker over the years, and won an Outstanding Performance award in 1969.

In 1971, Governor John Love awarded Sue as the "Handicapped Coloradoan of the Year." That same year, Sue received nomination by the AFAFC as Colorado's Outstanding Federal Handicapped Employee. She went on to become one of ten finalists for the Federal Civil Service and Department of Defense Handicapped

Employee of the Year. Sue greatly enjoyed the ceremonies in Washington D.C. In 1973, Sue went to work for the Department of Welfare in the Social Security office and officially retired in 1982, completing thirty years of dedication to the U.S. Government.

It was not long after retirement that DPS contacted Sue to teach English as a Second Language and to translate for Spanish-speaking families—her dream since college. After five years with DPS, she decided to change focus and devote her remaining retirement years more fully to her greatest loves—arranging Christmas parties for the underprivileged, raising money to send children to the Shriner's Circus each year, volunteering in her church teaching children's religious education classes and reading to preschool children. Sue received a Papal award for her work with the children from her church. Sue never let broken bones or unexpected illnesses keep her away from her life of helping others.

At the age of 81, Sue still lives independently, although she has help with basic household chores. Her braces and crutches stand in the corner now as she moves from room to room in her electric wheel chair. "I still like to entertain my friends," Sue said. "I make homemade spaghetti sauce and pasta or pork green chili and refried beans. Then we'll play bridge or board games."

Despite what many people may think, Sue's greatest difficulty in life has not been her polio. "I always knew that you do with what Papa Lord gives you. But to sell my handicapped equipped car and become dependent on others to assist me has been the worst part of all."

Sue continues to be an inspiration to everyone by her letters and phone calls of encouragement - "Have faith in Papa Lord!" "Don't give up!" "Accept what you get." "Pray a lot." "Laugh and remember that regardless of your limitations, life *is* worth living." Sue is truly a remarkable polio survivor—and an inspiration to all.

## Can polio be a blessing?

*By Bill Bradley*

The question seems an oxymoron, but here's one story that answers, "Sometimes".

In 1943, the midpoint of World War II, I turned 18 and was drafted into the army infantry. In time I went to Europe where I joined the Battle of the Bulge and subsequent battles that helped end the war in that theater. After a stint in the Army of Occupation I returned home in 1946 to be mustered out of service. An officer at the discharge center recommended I sign up for

the inactive reserves instead of taking a discharge—it would entail no work and it would preserve my rank in case anything unexpected happened in the future. It seemed a good suggestion and I accepted; I thought the US would be at peace for years to come.

Four years later the unexpected happened, the Korean War. Fighting started quickly and the Army needed experienced soldiers in a hurry; there wasn't time to wait for new draftees to be trained. So, the reserves were reactivated—first the active reserves, then, beginning in the summer of 1950, the inactive reserves. (*Con't. on page 8*)

## Can Polio Be. . . *(Continued from page 7)*

At that point I realized I was vulnerable: I had the experience and I was still young. It was an unsettling prospect. My life had just gotten back together after the three-and-a-half-year interruption: I was attending the University of Wisconsin, had found a major I loved (geology), had gotten married, and had a child. The thought of a second disruption, especially involving combat again, was agonizing. As the summer wore on the threat increased.

My senior year at school started in September. It was distinguished by the conflict between academic pleasure and the impending recall. I immersed myself in the academics because I knew the Army was immutable. Polio overtook me in early November. At its peak I was totally paralyzed below the waist. Then I began the slow, erratic recovery that so many post-polios have lucidly described. After a few weeks I was able to get around in a wheelchair.

That's when I received my orders to report for a physical exam, the first step in being recalled to active duty. By coincidence the exam would be held in my hospital. I thought: here's a chance for some good chuckles—I'll show up for the exam in my wheelchair. Instead of being amused, the Army people were puzzled about what to do with me; an order's an order, isn't it? It has to be carried out. So they started me through the exam. It didn't take long for them to realize the futility of it, and I was dismissed. Eventually I received my formal discharge papers.

I spent four months in the hospital and two years in physical therapy, after which I

walked with a long-leg brace and a cane (which, with minor modifications, are still my aids today). Even though I was out of school for that whole first year, academic progress continued without me. By the fall of 1950 I had completed all college and departmental requirements, and lacked only 15 hours of elective credits to graduate. Veterans with enough time in service could receive up to 15 hours of elective credits for a Bachelor's degree. Thus, without any academic effort on my part the University graduated me in the spring of 1951. I was mobile enough by then to start a graduate program in geology at Stanford University, which was completed in 1955. For the next 34 years I taught geology at the University of Colorado in Boulder.

A comment here about contracting polio. Enough uncertainty existed about why certain people got the disease that patients were given a questionnaire to try to identify patterns. (My case was unusual because it came in November, months after the summer-peak.) One of the questions was "Did you sleep on the ground recently?" As a matter of fact I had, a week earlier on a weekend field trip. The medical people were interested in that, but I doubted it had been important because I had slept on the ground a lot during my life. Decades later I came to a better explanation, stress. The fall of 1950 was a high-stress time for me. Part of it related to the academics—I was a new teaching assistant and I was taking some tough graduate courses; this part did not change during the fall. The other part came from the impending recall into the Army, and it increased steadily during that time. I now believe the two combined to make me vulnerable to one of the few bugs that hadn't yet gone south. *(Continued on next page)*

Finally, to return to the question at the start. For me, there's only one answer. Polio saved me from returning to war and all that would have meant. A good friend with army specifications identical to mine got his orders for a physical exam two weeks after I did, and he was in Korea before the end of

the year. One of my most vivid memories is the euphoria I felt when I knew I couldn't be recalled. That feeling undoubtedly helped my recovery and subsequent adjustments. Certainly, polio created new and major problems, but I'm glad to have faced them instead of the alternatives.

## And by the way. . .

A survey was taken at the September Educational meeting asking how people exercised. The results are in the chart below. Thank you all for your contributions. Hopefully, the activities listed below will open up options for others.

	No assistive devices	Wheel Chair	Brace(s)	Crutches Or canes Or Walker	Oxygen user	Ventilator user
Balance Ball			XXXX	XXXX		
Dancing	XXXX					
Downhill Skiing			XXXX	XXXX		
Exercise bicycle/ Exercise equipment	XXXX	XXXX	XXXX	XXXX		
Kaiser Silver Sneakers program			XXXX			
Physical Therapy			XXXX	XXXX		
Stretching exercises				XXXX		
Swimming/ Pool therapy		XXXX	XXXX			
Tai Chi			XXXX			
Video exercises— Wheel chair or other			XXXX	XXXX	XXXX	XXXX
Walking	XXXX	XXXX	XXXX	XXXX		
Weight training			XXXX	XXXX		
Yoga—on land Or in pool		XXXX	XXXX	XXXX		

\* One humorist at the meeting said that his exercise was to chase nurses on a catch and release basis!!!!!!

## In My Opinion. . .

*(Continued from Page 2)*

However, these experiences taught me that I needed exercise that I could do and do comfortably and safely, in an environment that I enjoyed, and with people that I liked and trusted. So, because I like to walk, I

moved to a neighborhood that had lots of trees and lovely landscaping and was easily accessible. I am still a “fair weather” walker, and I have “walking” neighbors, some of whom are about as speedy as I am.

*(Continued on the next page)*

**In My Opinion. . .** *(Continued from page 9)*

Also, the wisdom and guidance of my physical therapist has helped me develop my abilities in a safe and friendly environment and has kept me exercising regularly. As I live close to her office, I use its after-care program several times a week, where I do my prescribed exercises on their equipment. I think of her as my personal trainer and her facility as my gym.

I hope my story points out the issues of “do” ability and accessibility that face us polio survivors when we want to be physically “fit.” A doctor that knows you, knows polio or related neuromuscular diseases, and has knowledge of good resources can perhaps get you moving in the direction you want.

The rest of the exercise equation depends on your ability to take the time to research resources that will meet your needs, based on your abilities and your environment. And, this leads me back to our research on accessible warm water therapy pools, keeping in mind that hydrotherapy may not be a good choice for many of us for the reasons cited by Dr. Halstead.

According to one resource, one of the criteria for a warm water therapy pool is that both the water temperature and the air temperature be between 88° and 94° degrees. Based on these criteria, there are many such pools in the Metro Denver area, examples including but not limited to The Bronco Sport Center Pool (303-788-9266), and the Buck Recreation Center (303-797-8787) in the south Metro area, Easter Seals Colorado Pool (303-233-1666 ext. 1) in the central area, Healthone Bronco Rehabilitation

Center (303-451-7700) in the north metro area. However, for a more complete list, see the Rocky Mountain Chapter of the Arthritis Foundation web site at [www.arthritis.org](http://www.arthritis.org) for a listing of pools that are certified by the Arthritis Foundation and offer warm water exercises in the Rocky Mountain region.

When contacting any pool, ask the questions that speak to your specific needs, including questions about water and air temperatures, lifts, steps, accessible parking lots and entrances, and easily accessible dressing rooms. Water and air temperature are just part of the accessibility issues that will motivate a person to stick with a program.

Another resource for polio survivors is aquatic therapy. There are many aquatic therapy centers in Colorado that offer hands on Aquatic Physical Therapy, specialized exercise classes and WATSU(Water Shiatsu) treatments. The web site for more information is the Aquatic Resources Network at [www.aquaticnet.com](http://www.aquaticnet.com) or phone 715-248-7258.

These suggestions are offered not as an endorsement or recommendation in any way, but as a starting point for any search for a personal exercise program that might fit your needs.

Finally, on another note, the personal profiles in this issue are not directly related to exercise, but are opportunities for people to share their stories. Bill Bradley shares how he was able to see polio in a positive light and Sue Gonzales’ story is one of a lifetime of thriving in spite of her disability.

*Margaret C. Hinman, editor*

## A Statement about

### Exercise... (Continued from page 3)

- The plan should include a rotation of exercise types, such as stretching, general (aerobic) conditioning, strengthening, endurance, or joint range of motion exercises.

Polio survivors who experience marked pain or fatigue following any exercise should hold that exercise until contacting their health professional.

Researchers and clinicians cannot make a more definite statement until additional studies on the long-term effects of exercise and the effects of exercise on function and quality of life are undertaken.

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## **This Is Your Newsletter-----**

Colorado Post-Polio Connections is a newsletter by and for polio survivors, their friends and others who are interested in being part of our network. The editors and staff invite your contributions to the newsletter. If you have comments, articles, or suggestions for topics for future issues, please email us at [post-poliocolo@comcast.net](mailto:post-poliocolo@comcast.net) or write to us:

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Please include you name, address, phone number and email address in any correspondence.

**Our next issue will focus on attitude and mental health.** We need suggestions from you on what kinds of lifetime attitudes you have needed for you to be able to survive polio and its effects for our “And By the Way. . .” column.

### **Disclaimer**

The opinions expressed in this newsletter are those of the individual writers and do not necessarily constitute an endorsement or approval by the Easter Seals Society or the Post-Polio Advisory Council. If you have personal medical problems, consult your own physician.

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**FREE MATTER FOR THE  
BLIND OR HANDICAPPED**