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**Proceedings of  
Gazette International  
Networking Institute's  
Third International  
Polio and  
Independent Living  
Conference**

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May 10-12, 1985  
St. Louis, Missouri

Edited by  
Gini Laurie  
Judith Raymond

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## **Proceedings of Gazette International Networking Institute's Third International Polio and Independent Living Conference**

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May 10-12, 1985  
St. Louis, Missouri

Over 500 registrants, including polio survivors, physicians, and other health care professionals from around the world attended Gazette International Networking Institute's Third International Polio and Independent Living Conference held in St. Louis, May 10-12, 1985.

Foreign countries represented were Australia, Canada, Denmark, West Germany, The Netherlands, South Africa, Sweden, and Taiwan.

Conference topics on polio included the role of exercise, the management of pain, research, immunization, meeting the challenge of aging, recognizing the need for respiratory support, psychological adaptation to changing respiratory support, and living long-term with a ventilator. Guest speakers were Albert Sabin, M.D., who discussed "Conquest of Polio: Unfinished Business," and William Masters, M.D., who discussed "Sex, Disability, and Aging."

Leaders of the disability rights movement participated in panels on attendant care, national health insurance, and the American vs. the European model of independent living. Goals of the conference were:

- 1) to assist organizations in their efforts to conquer polio by worldwide immunization;
- 2) to work as a team of polio survivors and health professionals, and of organizations and coalitions of the elderly and disabled for networking, information, research, mutual support, education, treatment, and immunization;
- 3) to continue to relate the positive uses of the past polio experiences to other disabled, to elderly persons, and to other ventilator users;
- 4) to assist professional persons in offering informed choices to those facing prolonged mechanical ventilation by demonstrating past polio experiences;
- 5) to promote independent living, and to influence legislation for in-home support services, and national attendant care, the linchpin of independent living;
- 6) to affect positive changes in attitudes toward disability and aging.

# The Polio Experience: Positive Uses of the Past

by Gini Laurie

On the 25th anniversary of Dr. Sabin's polio vaccine, and the 30th of Dr. Salk's, it is fitting that this conference emphasize the positive uses that can be made of the past polio experience.

The polio experience of the epidemic years of the 1950s was concentrated in sixteen regional respiratory centers that were created and funded by the National Foundation for Infantile Paralysis, the March of Dimes. Those centers, the ventilators used, and home care system should be studied carefully today as models for the treatment and rehabilitation of ventilator assisted persons disabled by spinal cord injury, muscular dystrophy, ALS, and other diseases.

The centers were a pioneering and creative learning experience. Their multi-disciplinary teams included patients and their families. The centers cut the average hospital time from one year to seven months. Without the centers, 40% of those sent home on ventilators would have had to remain in custodial care for the rest of their lives.

Of vital importance was the positive attitude of the staff toward the patient's ability to assume responsibility for self-directed care at home. From the centers evolved a model system of home care of ventilator assisted polio survivors.

The first program was started in 1953 at Rancho Los Amigos Hospital in Los Angeles County to save money. The preparation for returning home was meticulously orchestrated, and included home evaluation, adaptations, and trial home visits. After returning home, an umbilical relationship with the hospital included medical care, therapy, and equipment maintenance. Payment for attendant care was included in the program, and disabled individuals were trained to hire and train their own attendants.

Then, as now, home care costs 1/10 to 1/4 less than hospital care. In 1953, that cost was \$13,500 per year vs. \$3,600 per year at home.

According to a study in 1984 by the American Association of Respiratory Therapy, the cost had jumped to \$271,000 per year for a ventilator assisted person in hospital, and \$21,000 per year at home.

Unfortunately, the original centers and the attendant care programs were closed in 1959, because donations to the March of Dimes dropped drastically after the success of the vaccines. Even more unfortunately, no state or federal program carried on the centers or the attendant care programs.

Nonetheless, polio survivors continued to live fully and productively in their own communities. They attended school, worked, married, raised children, and traveled, and many of them are here today — 30 years later — still living fully and productively.

Since our first polio conference in 1981, the experien-

ces of the respiratory polio survivors have become widely known. The past is being related to the growing number of persons who are ventilator assisted because of other disabilities or injuries.

The goals of that first conference were to pass on the 30 years of the polio experience of living with a variety of ventilators to other ventilator users; to share the knowledge of older polio-experienced physicians with younger physicians; to relate the aging problems of polio survivors to other disabled, and to elderly persons.

Our second international polio conference in 1983 in St. Louis drew 439 registrants from around the world. It triggered the interest of the medical community in the late effects of polio. It was the nucleus for a scientific symposium at Warm Springs, and for regional seminars and conferences in California, Minnesota, New York, and in Canada and Sweden; and for increasing media coverage and research.

The national publicity after the Warm Springs Symposium uncovered countless polio survivors who were facing new problems of physical and psychological adjustment. Our two conferences also called attention to other lessons to be learned from the past polio experience. They highlighted the initiative, self-direction, and creativity of polio survivors who had to learn to live with the minimum of gadgetry and equipment and the maximum of adaptability.

This conference of professional and disabled persons from around the world has even more exciting goals than the previous conferences. The goals are:

- To assist Dr. Sabin, who will be our guest of honor tomorrow night, Rotary International, the United Nation Children's Fund, the World Health Organization, Save The Children's Fund, and other organizations in their efforts to conquer polio by worldwide immunization.
- To work as a team of polio survivors, of clinical and research physicians, and of organizations and coalitions of the elderly and disabled for networking, information, research, mutual support, education, treatment, and immunization.
- To continue to relate the positive uses of the past polio experiences to other disabled, to elderly persons, and to other ventilator users.
- To assist professional persons in offering informed choices to those facing prolonged mechanical ventilation by demonstrating past polio experiences.
- To promote independent living, and to influence legislation for in-home support services, and national attendant care, the linchpin of independent living.
- To affect positive changes in attitudes toward disability and aging.



# The Role of Exercise

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## Frederick Maynard, M.D.

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There is confusion in the medical literature about terminology for post-polio problems. There is little agreement among physicians as to what to call the problems.

Many new health problems are being seen in the post-polio population. I would like to adopt the classification proposed by Dr. Lauro Halstead. First, there are new health problems that develop in this population which are unrelated to a history of polio or to the residual sequelae of polio. These are conditions like heart failure, cancer, and other diseases that can happen in anyone. Although they can confound the disability of post-polios, they are not a direct sequelae of polio.

Second, there are problems related to a history of polio, known as late effects or late sequelae of acute poliomyelitis, which have a known etiology. These are primarily musculoskeletal complications: deformities, nerve entrapments, degenerative disc disease, arthritis, and other problems related to aging and degeneration of the neuromuscular system. These problems are seen with a greater frequency in the post-polio population because of residual neuromuscular weakness and joint deformities.

Third, there are late sequelae of polio that have an unknown etiology. These include new neuromuscular degeneration. The terminology that I prefer for this is progressive post-polio muscular atrophy.

What do we mean by post-polio muscular atrophy? The word "atrophy" means a decrease in size of an organ of the body. Usually function is related to the size of an organ. Therefore, when there is atrophy, or a decrease in size, one expects a decrease in function. Muscular atrophy describes a decrease in the bulk or size of a muscle, implying less strength, or weakness. Atrophy cannot be as readily recognized by either the individual or physician as the weakness itself. Post-polio muscular atrophy implies the atrophy in muscles that is a residual of acute poliomyelitis. People who were left with weakness usually had a decrease in size of the muscles that were involved.

The use of the word "progressive" has also been controversial in referring to this problem. I believe that we should use it because the word "progressive" is what implies that it is new weakness. It is not the long-term residual weakness of acute polio and the original muscular atrophy. The weakness is greater than it was before and therefore progressive, albeit slowly progressive.

Some post-polios with new muscular weakness have a new disease entity, characterized by progressive abnormalities in neuromuscular function. We don't know where in the motor unit the problem is: the nerve cell, the peripheral nerve, the neuromuscular junction, or the muscle itself. These are the post-polios I wish to refer to as the progressive post-polio muscular atrophy group.

Epidemiologic studies by Dr. Mary Codd suggest that

20-25% of post-polios are experiencing new weakness. However, new weakness is not necessarily synonymous with progressive post-polio muscular atrophy because there are many causes of new weakness.

The most important differential diagnosis is between progressive post-polio muscular atrophy (new weakness) and disuse atrophy. We could say disuse weakness, rather than atrophy, because people don't come to doctors complaining that their muscles are smaller. They complain that they are weaker.

Now that we have discussed terminology, let us consider the role of exercise in post-polios. There are at least three major categories of exercise. There are exercises for conditioning the body, referred to as cardiopulmonary conditioning exercises, which develop endurance in muscles so that they can continue to produce tension for longer periods of time.

Second, there are exercise programs for increasing strength. Usually, these involve resistance to the muscle greater than gravity so that one is progressively lifting greater forces and trying to develop increased strength.

A third category that is important includes flexibility and range of motion exercises. These preserve the length and flexibility of muscles, tendons, and joints.

The concept of overwork weakness was first described by Dr. Bennett and Dr. Knowlton at Warm Springs, and describes a type of increased weakness that follows vigorous or strenuous exercise. A person becomes weaker following strenuous exercise and with maximum contraction is unable to lift the same weight as before the strenuous exercise. This weakness can be transient, lasting perhaps hours or days, or it can be persistent in severe cases, so the person may never recover the strength he or she had before the periods of overuse.

Exactly what role overuse weakness plays in the development of progressive post-polio muscular atrophy is unknown. Some of us believe, based on clinical observations with many polio patients, that the muscles which are used most vigorously in normal daily activities are the ones most likely to develop new weakness. This opinion is not based on scientific evidence, but on experience.

There are four important clinical questions to be considered concerning exercise.

1. When exactly should a post-polio person begin an exercise program? Or, in what clinical circumstances are strengthening exercise programs indicated for post-polios, especially those with progressive post-polio muscular atrophy?
2. What are the specific criteria for prescribing both the intensity and the duration of strengthening exercise programs or of conditioning exercise programs?
3. How does one differentiate disuse atrophy from progressive post-polio muscular atrophy?
4. When can strengthening exercises be harmful?

How does one differentiate disuse atrophy from progressive post-polio muscular atrophy? Dr. Bennett, in his original article about overuse weakness, said, "If you let a patient begin a resistive exercise program, one of two things will happen. The patient will, in fact, develop increased strength as a result of the resistive exercises or the patient will get weaker from the resistive exercises." If the strength increases, then we assume that there was disuse atrophy, which is reversible, and the person gains strength. If the person does resistive exercises and becomes weaker, this implies overuse weakness and the muscle was functioning at its best.

The management approach that I use when prescribing programs begins with individual assessment of the person. It is hard to generalize about exercise programs. It is very important to decide whether the patient is having new weakness from progressive post-polio muscular atrophy or from disuse atrophy associated with problems, aging, or lifestyle. If a muscle with new weakness is being used repetitively at near maximum loads in daily activities, and an EMG and other clinical signs suggest that this is a new process, a new post-polio muscular atrophy, then it doesn't make sense to prescribe resistive strengthening programs and subject the muscle to further stress.

The best example of this is walking. Normal walking relies heavily on the quadriceps muscle of the anterior thigh to stabilize the knee joint during stance. Several studies suggest that one only uses about 15% of the maximal strength in that muscle to stabilize the knee during normal walking. Some post-polios with a weakened quadriceps muscle as their acute polio residual are only able to walk using 80 to 100% of the maximum strength of that muscle. Therefore, when they walk every day for varying distances, they are, in fact, producing maximum contractions of that muscle repeatedly on a longterm basis.

Since cardiopulmonary conditioning exercises can improve the delivery of oxygen to muscles and promote greater endurance, they are more likely to be beneficial in all patients. If disuse atrophy is the problem that I believe is most likely from evaluating an individual patient, I recommend a careful trial of strengthening exercises as well as conditioning exercises. Whenever possible, conditioning exercises should be done, even in patients with progressive post-polio muscular atrophy. Conditioning exercises must never strain weakened joints since this may produce or aggravate pain. Therefore swimming is often the best activity for general conditioning in severely weak post-polios.

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### **Marvin Brooke, M.D.**

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I was a patient of Dr. Bennett at Warm Springs, and he told me and others to avoid overuse and possible weakness that might result from overuse. I have seen overuse in patients as I've practiced, but realized that I needed to know which muscles not to overuse specifically. It must be an individual assessment. There are some muscles for which overuse may not be a problem, and one must pay careful attention and use self-restraint.

It is important to measure baseline amounts of either

strength or endurance precisely and scientifically. A baseline period of seven months of observations is helpful.

We often measure the time of walking or climbing stairs. If it's over several months, we can note if there is a progression of weakness. If one is going to make a modification, whether it's exercise or some other intervention, measure in as precise and similar a manner what the function is. Then also try stopping it for a while and observing again if there's a change.

Polio survivors need to select the important function for them. The physician may want to strengthen a specific muscle for a specific function, but the polio survivor must choose the activity most important for him or her. Physicians need to use common sense, observe, and also be sure they do not generalize.

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### **Richard Owen, M.D.**

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In 1981, I attended the first polio conference in Chicago. I was very impressed by a speech by Dr. Maynard in which he said that he was pleased to look out on an audience (of polio survivors) of 50-year-olds who had 90-year-old muscles. I felt sanguine about that since I'd already passed 50, and I was still functioning fairly decently by my standards.

William Pope, a seventeenth-century English physician wrote, "Let me govern my passions with absolute sway and grow better and wiser as strength wears away; not by gout nor by stone, but by gentle decay."

The term "gentle decay" was my theme for a while until I found out that Minnesotans weren't really very accepting of "gentle decay," so we set up a polio clinic with an exercise protocol. The issues that we addressed were what Sister Kenny herself addressed 40 years earlier: mobility and flexibility. We then tried to assess the difference between disuse atrophy and post-polio progressive muscular atrophy. Does a weakened muscle which was previously strong, have the capability of being strengthened? We would choose a muscle that would be agreeable to the patient to work on, and we would then use a variety of muscle re-education techniques, or muscle training techniques to see whether or not we were capable of luring that muscle back into function.

Dr. Eric Mueller, a famous German exercise physiologist said, speaking of his group of old polios whom he had exercised many years after their polio, "In every muscle, unused for years, and seemingly paralyzed, slumbers the hope for easy rehabilitation." Testing the function by going through a gradual process of muscle re-learning was the goal of the initial part of our exercise protocol.

Another aspect is the matter of selecting muscles that, by tradition, weaken in almost everybody as they age, or as they become sedentary. Those are particularly the trunk muscles, the abdominal muscles, and the thigh muscles. We would select those muscles if, again, the patient found they were agreeable to work on, and work on specific strengthening programs in those areas. I think that with trunk musculature, we had the most gratifying response.

It's amazing how much abdominal muscles stop working when they are not used, and it's amazing how much

stress on the back and stress on walking is associated with a stomach that's hanging rather far out in front of one's center of gravity. We involve people with a trunk-strengthening program, specifically flexibility. We choose some muscles to strengthen after we've tested Dr. Maynard's concept, that about the only way to determine the susceptibility to overuse is to challenge the muscle.

By following one group closely, we indeed found that many people were able to bring muscles back up to a certain level, but that people slip back to the lowest amount of stimulation in using muscles. A person with polio, even though he or she might build a quadriceps muscle up to 30 or 40 pounds of single life, will lose that function if he or she doesn't use it. What we're doing in exercise is primarily of academic interest, and helps to prove to the individual with polio that he or she can do it.

One of the critical things to do before exercising starts is to analyze the ventilatory capacity of the individual. People that we see having most problems initially with an exercise program are people who had bulbar involvement and have either some variety of sleep apnea or oxygen deprivation. The cardiovascular conditioning aspect of this is very important. I wish we had a laboratory like Jackie Perry has, because her gait laboratory permits her to do stress testing. The cardiopulmonary status of the individual while he or she is in action would be one of the most useful pieces of research that we could do.

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### **Gerald Herbison, M.D.**

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I take issue with calling post-polio weakness atrophy because I think my patients talk to me about being weak rather than being atrophied. I think there's very little evidence indeed that there is a loss of nerves.

Dr. Maynard found minor abnormalities in the muscles, which are the hallmark of ongoing nerve damage, in only four patients of eighteen patients. It's a highly peculiar disease that would cause weakness in so many of us, since we find a paucity of evidence of nerve damage.

Dr. Codd found that there was evidence of 70% of weakness in patients. Sixty-six percent of her patients developed new weakness, and only 30% of those patients reflected any evidence whatsoever of nerve damage.

I think that there is a paucity of evidence for the notion that we have a slowly progressive disease.

If an adequate amount of nutrients are provided to a normally hypertrophied muscle fiber, that muscle fiber, then, will be able to maintain its integrity. When hypertrophied muscles are supplied with circulation, the circulation is insufficient and, consequently, there is a disintegration of the muscle. Once there is a disintegration of muscle, there is a loss of strength. It's physically impossible to carry out muscle activity with disintegrated muscle fibers which are degenerated or necrotic.

Dr. Bennett said that the problem with the loss of strength is not at all due to a loss of neurons. I subscribe to that completely. He mentions patients in his paper in 1957 where the patients were weakened, and then he protected the muscles and the strength came back. We have evidence that there is an overwork degeneration of muscle.

If nerves die, they don't come back, but if muscles partially degenerate, we know enough about muscles to know that they can regenerate. Indeed when Bennett protected the muscles they became strong again. It's the over and over usage of muscles that makes the muscles weaker.

Let me tell you the other kind of muscle activity that makes muscles weaker. If I use my hand, for instance, by using a reflex hammer to tap the knee of a patient, and I do it over and over again, my hand gradually collapses into a bent position. How many of you have carried a bag of groceries, and as you've carried that bag of groceries, that bag went down to the point where you're running to the counter to get it to the counter before you finally dropped it? It's that specific type of muscle contraction that seems to have the greatest damaging effect on muscles. It's the kind of muscle contraction that occurs when one squats to prevent oneself from falling. It's referred to as a lengthening contraction. Those are notorious for producing muscle damage.

Dr. Mueller, whom Dr. Owen mentioned, suggested the use of an exercise program that invariably did not cause decrease in strength. There's no threat to the muscle. I've never seen a single study, using his form of exercise, that led to muscle damage. He has used three successive contractions six seconds each, and those six-second contractions never caused a weakening of muscle. They caused an increase in the strength of the muscle. It's a muscle strengthening program that will lead to an increased force of contraction.

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### **Rubin Feldman, M.D.**

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An increasing number of patients are being seen in a clinical setting complaining of changes in muscle function which have begun about 20 or 30 years after the initial onset of acute poliomyelitis. These changes are characterized mainly by muscle weakness and fatigue. While weakness is something we can measure, fatigue is a manifestation which the patients feel as they continue to try to use that muscle. Both are frequently associated with muscle and joint pain. This pain sometimes can be easily explained, but other times may be of neurogenic origin.

The onset of a secondary weakness is frequently associated with an unrelated incident, such as surgery for abdominal problems, involvement in a motor vehicle accident, or a fall, necessitating hospitalization. After a period of relative immobility because of the incident, weakness starts, and progresses to the point where deterioration of general function occurs. This results in an increased need of additional ambulation aids, and sometimes the use of a wheelchair, which the person may not have required for many years.

The pattern of weakness which develops is virtually identical to that which occurred during the initial onset of polio. There is occasional muscle atrophy, that is, reduction in the size of the muscle associated with the weakness. As the weakness progresses, there is deterioration of walking ability, both in quality as well as in distance, and compromise of function in activities of daily living.

Since many of these patients are between the ages of 30 and 50, the additional stress because of this deterioration of function is very obvious. To this is added, unfortunately, the feeling of frustration because of difficulties in obtaining further information as to why this process is taking place.

When our patients are first seen in our clinical setting in Alberta, they supply historical data in a questionnaire which has been designed to identify the manifestations that are present during the initial onset of polio, the degree and area of muscle function recovery after the initial onset, the type of life-style and occupation that the person has been following, the question of the presence of any incidents that could have triggered the more recent decline, and finally the present circumstances and the topography and intensity of decreased function, both muscular and general.

Attention is given to the possibility of other musculoskeletal difficulties being present, such as osteoarthritis, rheumatoid arthritis, and any other associated musculoskeletal or neuromuscular problems, since it is very important to make sure that this is, in fact, post-polio syndrome, and not some other disease process.

Examination, besides a general examination, focuses on the determination of the degree of muscle strength in the trunk, and in all four limbs, with careful documentation of any areas of weakness demonstrated by any muscle groups, and the degree of this weakness.

If we find weakness, then electromyography, motor nerve conduction velocity studies, and repetitive stimulation studies are performed. These studies have permitted us to differentiate between weakness secondary to disuse, and a decrease in muscle function secondary to a recurrence of problems which could be relative to the initial onset of poliomyelitis.

Because the method of exercise will be different depending on whether weakness is secondary to post-polio syndrome or not, this differentiation becomes very important.

Finally, the patient's brace management is reviewed, if any bracing has been used since the initial onset of polio. Functional assessment is also performed. This evaluation then permits the development of a treatment program which is designed to strengthen all muscles that are found to be weak on examination. Those muscle groups that are weak as a result of disuse, or for any other reason other than anterior horn cell disease, are strengthened in the usual manner without too much concern about whether fatigue will be caused or not.

The weakened muscle groups that have been found to have changes on the EMG and on repetitive stimulation studies which are thought to be indicative of post-polio syndrome are provided with a strengthening exercise program that emphasizes nonfatiguing exercises.

Determination is made as to what amount of muscle contraction can be done with ease. Parameters that are used include the amount of weight that can be moved, and the number of repetitions through which this weight can be moved. Once this determination is made, the program, using progressive resistive exercises, starts at a level of about 50 to 60% of the determined value, to give us some leeway and to get the patient accustomed, not only to im-

provement in range of motion, but also to the idea of what the exercise is all about.

While the weight remains constant, the number of repetitions involved in the exercise of each muscle group is gradually increased over time until the patient demonstrates the ability to move the designated weight a total of about 30 repetitions. At that point, the weight is increased slightly. The number of repetitions again begins usually at about 5, and is gradually increased again until 30, or as high as it possibly can go before 30.

The weight is then further increased when possible. The procedure continues until maximum weight at the largest number of repetitions has been achieved without fatigue. Once fatigue becomes a factor and is present when exercise is done, it is felt that the maximum amount of exercise has been achieved. In addition, every effort is made to avoid fatigue throughout the entire exercise program.

This procedure is used for all muscle groups which have been identified as having weakness secondary to manifestations related to a previous onset of polio. Obviously, there is no exercise given to muscles which show no EMG activity.

If patients have had braces before, attempts are made to provide later polypropylene bracing having the same effect as the initial bracing, and therefore, being able to provide equivalent support with less weight. At times when the effect of exercise is not sufficient to provide appropriate support for joints, lightweight bracing is prescribed as a means of improving function. This orthotic management has turned out to be an integral part of the total management of these patients.

Initially, when we started treating these patients and giving them the same kind of exercise irrespective of the reason, improvement in function was, in fact, obtained in muscles weakened from what was thought to be disuse. We noted also, as was described previously, a decrease in function obtained together with an increased amount of weakness and muscle atrophy in muscles that were weakened as a result of post-polio syndrome.

When we change the approach to exercise, providing a nonfatiguing type of exercise for the muscles weakened because of post-polio syndrome, a strengthening effect was found. All of these muscle groups demonstrated an improvement in strength of from one to three grades in muscle testing.

With this improvement in muscle strength, attempts were then made to improve function using occupational therapy. This, together with improvement in orthotic management, ambulation training, and conditioning exercises, has provided the patient with improved function of ambulation and activities of daily living.

The presence of poliomyelitis 20 or 30 years ago does not, in any way, reduce the possibility of patients having problems associated with continued use of joints and musculoskeletal and neuromuscular problems found in the general population. In the presence of weakness, therefore, it becomes essential to identify the reason for the weakness and to differentiate between the weakness due to disuse and weakness secondary to post-polio syndrome. With electrophysiological studies, we've been able to differentiate between these two causes of weakness.

Pain occurs in patients whose joints have had less support because of weakness of overlying muscle. As such, it is not unusual to find shoulder pain in the presence of deltoid muscle weakness, and hip pain in the presence of hip abductor weakness. This is sometimes associated with manifestations of weakness elsewhere and appears to increase on exercise, particularly if fatigue results from this problem.

The use of nonfatiguing exercise applied to muscle groups that demonstrate weakness secondary to post-polio syndrome, results in slow, but steady strengthening of these muscles over a period of three to six months of consistently applied exercise in sessions attended two or three times weekly. I recognize that that statement reflects a difference in the division of health care above and below the 49th parallel. We have the opportunity of having individuals as outpatients, and if necessary, as inpatients, to provide not only the exercise, but the rest that is required between exercise attendances.

The intensity of exercise must be very gradually increased, and in the meantime, the patient must be supported emotionally so as to avoid the frustration that could otherwise occur. This method of treatment, together with occupational therapy to teach the patient how to improve function as muscle strength does improve, and appropriate orthotic and other management, results in improvement in general function which sometimes is comparable with the level of function which was present prior to the onset of these secondary problems.

We have now had follow-up of our first patients who were placed on this program, and who then were placed on a well-adhered to home maintenance, nonfatiguing exercise program for up to six months after they stopped physical therapy. We've shown that there is a beneficial effect that actually can be maintained. It is anticipated that this benefit will continue; but future follow-up will be needed to ascertain the long-term effects of this kind of exercise program.

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### Jacquelin Perry, M.D.

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I'm seeing about eight or ten new patients each week. Two types of patients are coming; those who are asymptomatic, and inquiring about the problems that they've heard about, how they can avoid them, and those who are symptomatic.

For the ones who are having pain, fatigue, and muscle weakness, a careful comparison of their previous acute polio experience with their current problems shows that the post-polio muscles are involved.

One of our problems in estimating patients' difficulties is that our customary manual muscle test, or testing for strength, has over-estimated capability. This was demonstrated many years ago, but got lost in the literature. A so-called normal muscle, by manual testing, may be only 75% of true normal. We've found out in other studies that in the thigh muscles or the quadriceps, the difference may be as much as 40%, so we've over-estimated what is really a normal recovery.

In addition, the grade of "good," or Grade 4, is only

40% of normal, so people with good to normal strength have the strength to perform their motions and their activities in a normal manner, but not necessarily the strength to take indefinite strain.

Our primary effort has been trying to avoid strain. We've been evaluating lifestyles, and to reduce the strain, providing orthosis sometimes and occasionally doing surgery to correct deformities.

Almost all my patients seem to have already tried an excessive exercise program and found that they've lost strength. They're extremely relieved when I tell them they don't have to do it, because everyone in Southern California does exercises, whether it's right or wrong. I also seem to have a rather large telephone practice across the country and I find the same experience, that they're relieved to find out that there is a real syndrome (and I object to the word "progressive" — I don't think it has to be progressive). I think the syndrome, basically, is a chronic overuse.

The majority of the patients are having their problems 30 years from their onset, which can be somewhat prorated to the intensity of their lifestyles. I have a second population in their seventies who got their polio in 1918 or 1921. They lived a more sedate life, and it's taken them sixty years to wear out.

We're obviously carefully evaluating the muscles and telling our patients which ones to be careful of. If they've had a history of an abrupt change of lifestyle, like retiring, and have weakness with no other symptoms, we've tried some gentle exercise and that group has profited. My current rules are that the never-involved polio muscles are the muscles to be used for cardiopulmonary conditioning. The other muscles can do anything that doesn't cause pain, doesn't cause chronic fatigue, and doesn't cause a decreased loss of strength. It's difficult to get people to think of everything they're doing, but if they use those rules, it will help them.

I'm very interested in Dr. Feldman's program. He has the ideal opportunity to protect his patients with an in-patient program. We're having to do it by getting them to change their lifestyles.

If I see patients early when they're first having marked symptoms, and they can change their lifestyle or put protective braces or crutches on, I've seen muscle strength recover. This is why I object to the term "progressive." The only justification I can see for the word "progressive" is that it may get better grants to support research.

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### Laura Smith, PT., Ph.D.

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I appreciate the opportunity to present the experience of the physical therapist on strengthening exercises for persons with post-poliomyelitis. We have seen over 150 people at the post-poliomyelitis clinic at The Institute for Rehabilitation and Research (T.I.R.R.) in Houston. There are two part-time physical therapists who are evaluating the post-polios: myself, who worked exclusively with polio in the 40s and the 50s, and my colleague, Marcia Mabry, who is a post-polio herself.

An analysis of 100 of the people we have seen shows them to have an average age of 48 years, with a range from

25 to 87 years (Table I). They are primarily females (66%), ambulatory (84% with or without assistive devices), and personally independent (91%). They are an active and productive group (Table II). Out of these 100, 64 are employed, 11 have taken early retirement, 61 are managing a home, and a number are extremely active in community, profession, sports or travel.

**Table I**  
**T.I.R.R.**  
**POST POLIOMYELITIS CLINIC**  
NO. = 100

|   |    |                       |    |
|---|----|-----------------------|----|
| Age - $\bar{x}$ 48 years (25 to 87 years) |    |                       |    |
| Years from onset $\bar{x}$ 37.7           |    |                       |    |
| Females .....                             | 66 | Males .....           | 34 |
| Ambulatory .....                          | 84 | Wheelchair .....      | 16 |
| Independent .....                         | 91 | Needs Assistance .... | 9  |

Most people have come to the clinic with new problems and concerns, which include fatigue, muscle weakness, pain, cramps, and decreased functional ability. Neither my colleague nor I, however, have seen any of the post-polios in which we would recommend strengthening exercises or even endurance exercises for these new problems.

**Table II**  
**T.I.R.R.**  
**POST POLIOMYELITIS CLINIC**  
**ACTIVITY LEVELS**  
NO. = 100\*

|                               |    |
|-------------------------------|----|
| Employed .....                | 64 |
| Homemaker .....               | 61 |
| Community, Professional ..... | 31 |
| Sports .....                  | 20 |
| Moonlights .....              | 3  |

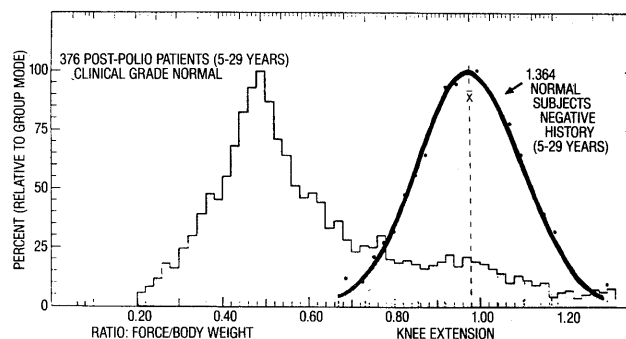
\*Individuals may participate in several activities.

Physical therapists have long known how critical the application of strengthening exercises were for polio patients. Even in the chronic stage where we were using resistive and repetitive exercises to increase the size of muscle fibers and to encourage the sprouting of nerve fibers, exercises were monitored carefully to avoid loss of muscle strength. Muscle testing was done at every treatment, even though it wasn't recorded. If a decrease in muscle strength occurred, there was too much activity or exercise. We would change our focus and give that muscle group or muscles less activity and concentrate on another area. Plateaus were warnings to be careful or the message that the maximum amount of strength had been gained. This occurred at nine to twelve months from onset.

Even though by muscle testing a muscle could take maximum resistance, and was graded a 5, or normal, the muscle could have lost up to 50% of its nerve cells (Sharrard 1955). Clinically this was also demonstrated by

Beasley's work as shown in Figure 1 on quantitative muscle force testing (Beasley 1960). Normal subjects were tested for the pounds force the quadriceps muscle could exert and compared to the force produced by patients with post-poliomyelitis who had a muscle test grade of "normal". It was found that few of the post-polio muscles were in the normal range and they averaged 50% less in strength than normals.

**Figure 1**  
**KNEE EXTENSION**  
**QUANTIFIED SCALING OF PARESIS**



*Ratio of knee extensor force and body weight in normal subjects and post-polios with a muscle test grade of 5 or N (Adapted from Beasley 1960).*

Functionally, over these many years, the weak muscles have been called upon to perform at high levels of their capacity. Strong, or truly normal, muscles have also been called upon to do a bigger job in order to compensate for other muscle losses. As the new problems developed in many people, they turned to exercise — weight lifting, jogging, aerobics, or swimming. Exercise helped at one time, but now they reported that instead of gaining strength, their problems were becoming worse. In many of the people that we evaluated, the muscles seemed exhausted. Their contraction was of a poor quality. They had a hesitancy to want to contract. They cramped easily. Some of them twitched at rest or in activity.

Rather than adding to the burden of the work load of these weak muscles, or overworked normal muscles, we have sought to decrease their burden by trying to get the body operating in a more normal and efficient manner with less use of muscles, and therefore with less use of energy. In sitting, standing, or walking, the normal body uses very few muscles at a low level of their capacity and provides the muscles with brief and frequent rest periods. To do the same activities, however, the post-polio must use more muscles, at a higher level of their capacity, and frequently without permitting periodic rest periods.

Our greatest initial success has been in restoring the erect position with better seating. People are sitting for hours per day in a slumped position in desk chairs, dining chairs, cars, or in wheelchairs that are not supporting the lumbar spine. We have been using lumbar rolls, balance chairs, corsets, and secretarial chairs to restore the lumbar and cervical curves. This in turn decreases the constant muscle contraction in the neck, shoulders, and back; hanging on ligaments; and pain from these sources.

In standing, the principles are similar. We work to gain weight-bearing through bony support, or through orthotic support, rather than through muscular contraction. For example, people with a stronger leg have probably spent most of their lives bearing most of their weight on this leg which requires continuous muscle contraction at a higher level of muscle capacity. If the person was an amputee, we would be concerned about getting a prosthesis so that the good leg did not wear out. With a post-polio, frequently a heel lift, a short orthosis or correction of their current orthoses permits the weak leg to bear its share of weight and reduce the work of the stronger leg.

In walking we work to gain the erect position and to decrease abnormal movements which increase energy expenditure. Many people are looking at the floor as they walk because they are afraid they are going to trip, their knee is going to buckle, and they are going to fall. This slightly flexed position causes continuous and abnormal back muscle contraction and, eventually, pain. By taking away the need to look at the floor through use of orthoses to pick up the toe or stabilize the knee, the person can

become erect and eliminate the continuous contraction and overuse of muscles with resulting decrease of pain.

Although we are not advocating strengthening exercises, improved alignment in sitting, standing, and walking, along with decreasing non-essential muscle activity has decreased pain and fatigue and provided a sense of increased muscle strength. For ongoing exercise programs, we are recommending beginning Yoga, relaxation exercises, pool exercises done easily, recognizing that a muscle can be exhausted in water just as easily as on land. Exercises of body awareness and movement such as the Feldenkrais exercises or Tai Chi are reported by many as providing a feeling of well-being and improved function.

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# Questions & Answers

**QUESTION:** *I am a PT from Cleveland, Ohio and my name is Bernice Krumbansl. Have you observed any Charcot joints in the old polios?*

**DR. MAYNARD:** A Charcot joint is a degenerative change in a joint associated with loss of sensation in the joint. It is seen in a variety of medical conditions.

**DR. PERRY:** I've not seen Charcot joints because the cause is not there. Polios have excellent sensation. I have seen shoulder joints with severe degenerative arthritis from crutch walking.

**DR. MAYNARD:** I would concur. I have not seen a Charcot joint in a post-polio either.

**DR. FELDMAN:** I haven't seen Charcot joints either, but I would hasten to say that what Dr. Perry is saying about the degeneration of joints because overlying muscles are so weak is certainly something that we see frequently.

**QUESTION:** *I'm Joyce Oliver from Richmond, Indiana. Is anyone studying the effects of cold? If my hands get cold, they quit working.*

**DR. HERBISON:** With every one-degree decrease in temperature (Centigrade temperature), there is a fall-off in strength of about 10%, as I recall. If you're in an air-conditioned room, you're obviously going to be weaker than

if you're in a warmer room. This has been shown any number of times on normal individuals. I'm not aware of anybody who's done this in weakened muscles, but I've done it any number of times in normal muscles. It's not based on circulation. One reason has to do with the synchronous activity of muscle. If the nerves become cold, then there is a decrease in synchronization of the contraction of the muscle fibers. All the muscle fibers don't contract exactly when you want them to contract. One contracts now and a little bit later, and a little bit later, and a little bit later — they don't sum up to make a forceful muscle contraction. Eventually there's total blockage of nerves once the muscle becomes cold enough, and consequently, if you block the nerves, there're no messages reaching the muscles, and one gets weaker.

**QUESTION:** *I'm Mary Lou Drosten from St. Louis. I have a very bad heart, which is weakened, and no cardiologist has connected it to the overuse of what muscles I have. I can't find any information that has to do with the condition of the heart.*

**DR. MAYNARD:** The question is, "What's the relationship of heart disease to a history of polio?" If a person is muscularly impaired from polio, and if he or she has a



normal heart to begin with (there is not another disease or abnormality), then they are unlikely to be able to stress the body's circulation sufficiently to strain the heart. The capacity of the normal heart would easily be able to fulfill the limited circulatory demand of a muscularly impaired person, even though the muscular system was maximally stressed. To my knowledge, we have no statistical evidence to suggest an increased incidence of cardiovascular disease in polios.

**DR. JESSIE EASTON:** Recently, I was using the *Index Medicus* and in the 30s and 40s, people were writing about hearts being affected during the acute stage of polio. If there were acute cardiac complications, they would be giving problems later on as we undergo "gentle decay."

**DR. PERRY:** I think another possibility would be some cardiac deconditioning for lack of a challenge which then would make them more sensitive to other kinds of lesions such as atherosclerosis. With a superimposed problem like arteriosclerosis and coronary artery disease, there would be a deconditioned heart for the lack of exercise due to the lack of muscles to challenge it.

**QUESTION:** *My name is Judy Grosner from Connecticut. Could you tell me if or when there will be agreement on the name for this particular condition? We've heard three this morning. The latest is post-polio sequelae. I heard that syndrome was out, and post-polio muscular atrophy was in disuse. I'd like to know if the group has some consensus, or perhaps would consider reaching one.*

**DR. MAYNARD:** How one ultimately gains consensus in the medical community is a good question. It takes time, and eventually when it's clear what the disease process is, then probably a name will fall out that best describes it and everyone will use. As long as it's still confusing as to what the cause is, I suspect there will continue to be some lack of agreement.

**QUESTION:** *My name is Richard Katz. I'm a physician at the Rehabilitation Institute of Chicago. I was wondering if you might like to comment on the concept that there's a drop-out in the number of motor neurons or nerves to muscles that occurs with polio even in the muscles that are not affected.*

*Single-fiber EMGs show that even in the muscles that are clinically normal, there is reinnervation which has occurred. Those muscles show signs that even though they weren't clinically affected by polio, they were indeed. Isn't the concept valid that there's a drop-out of motor neurons in patients who suffer from polio, and as they're getting older, the normal decay of motor neurons which occurs is happening and occurs from much of the weakness?*

**DR. MAYNARD:** There is nothing wrong with that concept, which came out at the first polio conference when we were focusing on aging. There is a very small percentage decline of motor neurons with aging, not more than about 20%. Given the right patient with just the right mix

of cells lost from polio originally, age-related losses may play a role, but it seems unlikely. I think Dr. Herbison's line of reasoning is good as to why it probably isn't the cells themselves that are dying off. It remains on the list of possibilities as to where the neuromuscular problem lies. It could be a metabolic problem in the cells itself that's being manifested in the axons or something distally.

**QUESTION:** *One of the physical therapists talked about twitching for the release of muscles. I walked with braces and crutches up until the last two years. I still use them on evenings and weekends and whenever there is inaccessibility in buildings. I have a lot of twitching and hard times sleeping due to that. Is that a symptom of overuse?*

**DR. MAYNARD:** I don't know that we know the answer. If the twitching is unassociated with weakness, or pain, then it becomes more complicated to interpret. Certainly most of us would agree it's not a good sign, whether it's directly related to exercise or not.

**DR. HERBISON:** An innumerable number of joggers twitch after they jog, and there's no evidence of progressive muscle damage in them whatsoever. I think that that's one of the fallacies to imagine that fasciculations, the twitches that you're referring to, are automatically related to progressive neuronal death. In those individuals with fasciculations, there was no other evidence of any ongoing neuronal damage.

**DR. PERRY:** Athletes who are twitching afterwards are also straining. They are willing to accept some penalty, because they still have enough tissue vitality they can recover. There's good evidence that they are damaging structures, not at the neural level, but in the muscle itself. You are demonstrating overuse of the muscle fibers, and that's one of the reactions to it. It's happening in pianists who are overdoing it, it's happening to super-marathoners, it's happening in our spinal cord injury patients. They're all wearing out their muscles by being super-abundant, as if exercise could be unlimited.

**DR. MAYNARD:** Twitching can occur in totally normal people. Stress, caffeine, and other things can aggravate the problem of twitching, but a post-exercise twitch, again in the context of a post-polio muscle that's already weakened, I would say probably is deleterious.

**DR. FELDMAN:** My strongest suggestion would be to have yourself examined and identify, not only the type of exercising you are doing, but general lifestyle. See how you can modify your function so as not to get yourself totally into a wheelchair. Modify the way in which you're doing things with the help of others so that you can carry on with what you're doing.

For the sake of those members of the audience who are still concerned about reports linking post-polio syndrome with amyotrophic lateral sclerosis (Lou Gehrig's disease), could we have agreement from the panel members that no such relationship exists? Response from all the other panel members, "I agree."



# The Management of Pain

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## Stanley Yarnell, M.D.

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Since December, 1983, 50 new patients have been seen in the post-polio clinic at St. Mary's Hospital, the ages ranging between 6 and 84. (The six-year old is not included in the statistics, but the case should remind people that polio is still a problem.) People who came to the clinic complained that they couldn't do what they used to be able to do, because of weakness, pain, fatigue, or some combination of all of those.

What were the common causes of pain? One was degenerative arthritis which I term wear-and-tear arthritis. Wear-and-tear arthritis is more a problem with people who have had difficulties with either long-standing muscle weakness or muscle imbalance contributing to altered biomechanical factors, or because of muscular tightness or joint laxity, leading to the wear and tear of the joint. With peripheral joints, it was the shoulder joint first, then the knee, then the hip, then arthritis at the foot-ankle and at the wrist.

With wear-and-tear arthritis or degenerative arthritis early on, there may be some breakdown of the cartilage and some erosion of the underlying bone. Eventually there can be some bony thickening, and finally some bony spur formation. The joint itself can get a gnarly look about it. It's a problem for people who have been using crutches or canes, or pushing themselves around in chairs for many years, or people who have been using primarily their one arm to do the things that they have to do. All of that, with a bit of muscle imbalance super-imposed, or even without any muscle imbalance, can lead to wear-and-tear arthritic changes. The shoulders and the wrists, which were not meant to be weight-bearing joints like the knees, the hips, and the ankles, are put into that role which can lead to problems.

There can be problems with the back as well. Of those 50 people that we saw in the polio clinic, 100% had scoliosis, whether the scoliosis was visible, or what we saw from x-rays of the back. There was associated muscle weakness, and some curvature to one degree or another.

If the disc which cushions the vertebrae in the back takes a lot of abuse for one reason or another, or becomes a little desiccated over the years, it can be a source of pain. The pain doesn't necessarily hurt right at the spot where you might think it would. A disc might be a bit degenerated, and one might have some back pain, but frequently it can refer pain in other places. For example, if it happens up in the neck, frequently pain can be experienced in the shoulder, or in the front of the chest, or someplace down in the arm. One might feel it in the muscle.

Spondylosis (arthritic changes of the facet joints in the back of the vertebral body) may be associated with the disc flattening and allowing too much weight-bearing to take place in those little joints, or it could be associated

with some of the curvature and rotation of the scoliosis. It could be because of an abnormal curve in the back, or a lordosis, a swayback that can cause wear and tear on the facet joints. They may hurt in the back, but they may also hurt in other locations.

Sacroiliac joint pain is another problem. The sacrum is the bottom end of the vertebral column — the spine, and it connects to the pelvis. It's that connection that is the sacroiliac joint. Frequently, people who either have a leg length discrepancy, or have scoliosis and the pelvis is not exactly straight, but tilted a bit, have gotten into some problem with pain in the sacroiliac joint from that bit of being lopsided. It hurts frequently in the buttocks or thereabouts. There are some seating modifications that can help.

Lumbar stenosis is generally a problem of older people. Some post-polios have also had lumbar stenosis which accounted for the pain that they had, primarily in their legs and primarily after they'd walked a fair amount or had exerted themselves in some way involving their legs.

Non-articular structures refer to soft tissues not in the joint, and they may be ligamentous structures, bursae, or tendons that help hold the joint together.

About 66% of the post-polios we saw had joint contracture or joint laxity. For example, with a shoulder not well-supported by normal muscle that hangs down out of the socket, the joint capsule and the support structures get stretched over a period of time. Contracture is a tightening up of the tissues around the joint.

Soft tissue tightness is another problem in the trunk muscles, the chest wall muscles, and the abdominal wall muscles. It may be associated with some degree of scoliosis or, for some people, from sitting slumped because of one degree of weakness or a change in posture over a period of time.

Soft tissue tightness can be associated with some discomfort, especially if it gets stretched suddenly. The muscles have their own tendons that insert onto the bones, and the covering around the bones, the periosteum, is loaded with nerve fibers that sense a lot of things. If one suddenly tugs on that tightened muscle where it inserts, it may cause some discomfort. Other commonly tight soft tissues are the hamstrings and the iliotibial band.

The gluteus and tensor fasciae latae muscles attach to the iliotibial band, a long, thick, tendinous-like band that goes down to the knee. It crosses the hip and the knee, and is frequently a problem if it gets tight in post-polio.

Rectus femoris is a hip flexor. It's one of those muscles that helps pick up the leg, and flex the hip. Frequently it becomes tight, especially in people who are still ambulating, but with a fair amount of weakness. It has the effect of pulling them down over a period of time if it gets tight.

Carpal tunnel syndrome is something that can happen in the general population as well. It can happen to

women when they're pregnant and retaining water in their hands. The median nerve passes through the wrist to supply muscles of the hand and sensation for the fingers. The nerve can become compromised and cause pain. It's also associated with numbness and tingling in fingers frequently. It bothers people, wakes them up at night and can result in forearm pain.

Bursitis is another problem. A bursa is a small fluid-lined pocket so muscles that are gliding back and forth over each other don't build up a lot of friction, but it can become irritated and painful. Bursae are at the shoulders, the elbows, the knees, and hips. There are a lot of bursae that can potentially become inflamed.

Tendinitis, an inflammation of the tendon where it crosses a joint, is a problem.

Muscle tension headaches sometimes associated with anxiety, or with scoliosis or degenerative disc disease in the neck, is another problem.

Fibrositis pain syndrome is usually associated with some underlying degenerative changes in the spine. In most polio people, it can produce pain in the muscles. It can be in any of the shoulder girdle muscles, and if a tender spot is pressed, it can cause a funny feeling in the fingers.

Ulnar compression neuropathy is where the ulnar nerve passes around the elbow and supplies muscles in the hand, and forearm, as well as sensation in the fourth and fifth fingers. If compromised, it can cause discomfort.

Tarsal tunnel syndrome is similar to the carpal tunnel syndrome, but it's in the foot and can cause burning discomfort.

With lateral femoral cutaneous neuropathy, people experience some burning discomfort or odd feelings in their thighs from compression of another little nerve that comes out over the top of the pelvis and down.

Thoracic outlet syndrome is primarily a vascular problem in which the blood vessels that go down into the arm can get pinched a little bit at a variety of places, either in the neck or a little bit lower. It is associated with scoliosis.

People with a variety of pain complaints had fairly conventional explanations for those complaints. Usually the problems were related to either muscle imbalance or muscle weakness, or altered biomechanical factors because of those two things, or joints serving as weight-bearing joints that weren't intended to be, or joint contracture soft tissue problems that could lead to neurological sources of discomfort.

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## **Frederick Maynard, M.D.**

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My experience with pain problems in post-polios is similar to Dr. Yarnell's. There is a long list of causes that are degenerative diseases of the neuromuscular and skeletal system. Usually I can find a specific cause for pain, but there are pains for which I cannot find a cause.

Polio survivors have struggled for a long time to overcome their impairments, and have often experienced a lot of chronic musculoskeletal aches and pains. They're likely to push themselves to continue with activities that they've

been able to do in the past, even when they may develop pain which I think the majority tend to ignore.

They are likely to also deny or be unaware of any new weakness which begins insidiously, whether it is from normal age-related slowing down, disuse, or PPPMA. People with this kind of insidious loss of strength are at very high risk for many acute and chronic musculoskeletal inflammatory conditions. They try to do what they always have been able to do without difficulty, but now if they have lost the reserve strength in the muscle, they strain the muscle or some other part of the skeletal system and end up with an inflammatory pain condition.

One can strain either the contractile unit (the muscle and the tendon that shortens when one contracts muscle) or the soft tissues. The soft tissues include supporting ligaments around joints, and fasciae, which are fibrous coverings of the muscle bundles themselves.

If one produces chronic high forces around some ligaments, they become stretched out. Then the joints become unstable so that the mechanical forces across them lead to degeneration of the cartilage, and eventually the type of degenerative or strain arthritis that Dr. Yarnell mentioned.

Of the common pain problems, nerve entrapment syndromes are particularly frequent, especially carpal tunnel syndrome. The majority of patients who complain about symptoms around their wrists do have slowed median nerve conduction on electrodiagnostic exams and they are usually crutch or cane walkers. We have done biomechanical analyses through the Ergonomics Laboratory at the University of Michigan to analyze what is the best position of the wrist and hand for weight-bearing forces to be transmitted through the arm to a cane or crutch. The majority of cane and crutch grips that people use cause hyperextension of the wrist when pushing down. Mechanically, because of the anatomy of the wrist, this narrows the space that the median nerve goes through. It isn't surprising that chronic weight-bearing and wrist hyperextension stretch out ligaments and predispose to median nerve problems.

I have tried to manage two post-polio patients — long-term ambulators who developed carpal tunnel syndromes — by altering their crutch grips. I have used a built-up crutch handle that allows the wrists to remain in a more neutral position when weight-bearing on them. One person was quite pleased with the new grip handle and has continued to use it without difficulty. The other has had several different modifications of the handle. Each modification seemed to create some pain and discomfort someplace else in the wrist.

Steroid injections are occasionally given for carpal tunnel syndrome but they should only be done once. If one continues with abnormal forces across the wrist, I don't think they make a lot of sense. If a person is uncomfortable because of tingling and pain at night, the traditional resting splints that keep the wrist out of hyperextension often help.

Peroneal nerves are also subject to pressure injuries in normal people. The biggest problem with peroneal nerve injuries in the polio group is with brace users, because it's easy for braces to slip or become otherwise malaligned. Muscle atrophy may cause the brace to be

fitted improperly, and it's easy to put excessive pressure on the peroneal nerve which is on the outside of the knee just below the knee joint.

Shoulder bursitis has been very common in my experience. Pain occurs during shoulder movement. The typical case shows a painful arc during shoulder abduction. There are many bursae around the shoulder, and it becomes important to diagnose exactly which bursa is causing trouble. Once that has been done, there are many effective and fairly traditional physical medicine techniques of managing bursitis. They include resting, sometimes for a period of days and perhaps with a sling to prevent use of the arm. One has to limit rest to a short period of time, or too much disuse atrophy may develop.

Anti-inflammatory drugs can be useful. Steroid injections have been effective in the normal patient population, but I have steered away from them in the polio population unless it is a person whose problem is quite sudden in its onset. If it's a pain problem they've had for more than six months or for several years off and on, my experience with steroid injections isn't very good in normal people having that history.

There are a lot of useful techniques in physical therapy for dealing with bursitis. Ultrasonic treatments are one of the more effective ones in my experience.

In terms of tendonitis, I talk about tendonitis and myofascitis together. They are strain syndromes with pain in the muscle areas, diffuse and not well-localized. They are most common around the shoulder girdle. The real problem with shoulder myofascitis is how to rest the muscles adequately, especially the supporting shoulder girdle muscles.

Treatment methods that I have tried include salicylates, that is, aspirin in its various forms, as long as a person isn't allergic and the stomach will tolerate it. I believe that people get more relief from their tendonitis, muscle aches, and myofascial pain with aspirin than any other drug. For those who can't tolerate it or for which it is unsatisfactory, there are a whole host of medications known to physicians as non-steroidal anti-inflammatories, including Motrin, Clinoril, Naprosyn, and others. They are worth a trial and error approach to find out if one of them will effectively decrease the inflammation and control the pain.

The use of local heat treatments either by the person at home, or as part of a physical therapy program can be helpful. One should consider rest and look at altering activities. If an activity is straining painful muscles on a chronic basis, such as walking, one usually must stop the walking, or the strenuous activity for a period of time in order for the muscles to heal.

A new technique that we've used in our physical therapy department is known as phono-phoresis. It involves ultrasound used in conjunction with a steroid cream. The ultrasound promotes absorption of some of the steroid locally through the skin. If it's a tendon or a myofascial inflammation that's fairly superficial, we think that one can probably get some absorption to the involved tissues. Our physical therapists who have been using this technique have been quite pleased with the results in post-polio patients. It can be done many times and there is less risk than with injected steroid.

Neuroprobe is another new physical therapy tech-

nique that's being used in chronic myofascial pain problems. It's based on the concept of trigger points (localized discrete areas in muscles) that, when local pressure is applied, produce severe pain. Therapy for trigger points can be quite varied, including stretching the muscle or using local anesthetic injections. Lidocaine and Novocain injections in the trigger points can produce not only short-term relief of pain, but many times eliminate the problem. Neuroprobe uses a special type of electric current. It's a high-frequency stimulation in a trigger point area than can be quite painful for the short term, but seems to be followed by some persistent relief of pain. When it is used in conjunction with a stretching exercise program and activity pacing, a majority of people have been helped.

The most common neck pain is the typical neck pain of degenerative arthritis that may or may not be also associated with cervical radiculopathy. Radiculopathy means that the nerve root itself is being pinched. It can produce weakness, which could be confused with PPPMA.

I manage cervical disc disease and neck pain syndromes with traction treatments. Disc disease does improve with traction and it is a useful way of confirming the diagnosis. Manual traction is applied first. When it seems helpful, or relieves the pain temporarily, we usually set people up with home traction units.

The chronic neck muscle strain syndromes are more difficult to treat. Isometric neck exercises, stretching, range of motion, and relaxation therapy (whether it be yoga or other types of meditation) can be helpful. It's difficult for desk sitters, typists, writers, etc. to control neck tension building up and producing pain. If one has weak head and neck muscles that are being used functionally, one can chronically strain these muscles. These are difficult problems without simple solutions.

Back pain commonly results from disc disease and may include radiculopathy. It can be treated in the usual methods; traction, rest, heat, postural exercises, manipulation, and drugs to control pain.

The chronic back strain syndromes that occur in the polio population are more unique to this group and trickier to treat. The strain can involve the sacroiliac joints, or some of the ligaments in the low back, as well as the paraspinal muscles (the muscles of the low back). They are usually associated with long-term deformities in the polio population such as the short leg and the long-standing limp. Watch people with a limp, and watch the bones of the back. There is major twisting with each step that is not a normal mechanical twist that the back's anatomy was made for. It produces excessive stresses on the joints that lead to degenerative phenomena.

Pelvic obliquities (not only is the leg short, but the pelvis is often smaller on the one side, or malformed, or becomes rotated) distribute forces in a way that stresses various tissues. The largest part of my post-polio clinic group that had back pain as their major complaint did have associated leg length discrepancy or pelvic obliquity.

We try to correct the leg length discrepancy with shoe lifts. A number of my patients remembered they'd had shoe lifts many years ago when they were kids and now they're having to go back to shoe lifts. Many times we have to return to adding braces or crutches in order to alter the biomechanics of their walking and decrease

strain on the tissues that are inflamed and hurting in the low back.

These measures need to be combined with flexibility and stretching exercises. I have found the manual manipulation techniques that our physical therapists are using to be very helpful: restoring normal joint play and joint laxity, realigning the pelvis when that's possible, using heat and ice before those manipulations or afterward to control the pain.

The weak abdominal muscles that are common in post-polios contribute to the loss of stability in the back. If they can't be strengthened, then the use of a corset or abdominal binder again protects and puts less force on the lumbar spine and is likely to help the back pain. I agree with the earlier comments about the lumbar pillows in wheelchair users with back pain. Usually that is a major part of their problem.

I've seen at least two or three cases of chronic progressive lower extremity edema in long-term flail legs that has been quite painful.

The question that's hard for both patients and doctors to answer is why walking or another activity that someone did in the past and didn't produce pain, now all of a sudden produces pain. I think we're dealing with aging collagen tissue — the supporting tissues of muscles, joints and ligaments. It loses its elastic properties with age. This is well-known from geriatric medicine literature. When collagen becomes stiffer and less flexible, it's more subject to strain. The normal aging population is much more subject to muscle strain and inflammatory conditions than the younger one.

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### **Glenn Reynolds, M.D.**

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The rationale for treatment of pain problems from degenerative changes secondary to poliomyelitis begins with prevention. Prevention can only be effective if one understands the natural course of the disability that has brought about these changes and induced a pathologic sequence of destructive change. Therefore, the hallmark of prevention and treatment is, first of all, centered around joint protection. This requires insight and education of the physician, therapist, and the person with these post-polio changes. A healthy understanding of the change of kinesio-logic forces (those of muscle function), and their alteration is important. Enhancing repair of these changes depends on good nutrition, good blood supply, reduction of swelling and inflammation, and weight reduction.

I mention the matter of weight reduction as many post-polio patients find that as muscle mass is reduced, so is energy expenditure. Therefore, a relative caloric excess is present which promotes obesity in the post-polio person and adds to the wear and destruction of the joints.

In certain circumstances, the actual deposit of fat adjacent to some spondylitic or hypertrophic neural foramina in the cervical or lumbar spine can add to the compromise of the nerve. With added pressure, more inflammation and swelling is present, there is less effective circulation, and diminished nutrient repair. Hence, there is more pain and destruction. A "dog with its tail in its

mouth" condition exists, and the problem keeps going around in a circle.

The post-polio person often uses the head and neck to lever the torso when in bed or against furniture for assisted movement or balance. Degenerative changes occur from excessive activity, and spondylitic or hypertrophic degenerative changes occur about the vertebral bodies and articulating facets. This results in these joints between the vertebral bodies producing spurs and bony overgrowth. I have seen many people doing this, working their way across the bed. A great deal of excess movement and body force is therefore placed upon the cervical spine. In addition there occurs degeneration, often producing direct nerve pressure, or the development of foraminal compression syndromes on the nerves that leave the spinal cord. Dr. Maynard has just referred to these nerves.

One often feels a grating sensation with or without pain in the neck or radiating into the arms and hands, and up into the head. Pain may cause reactive muscle spasms. The prevention, insofar as possible, is to avoid or minimize using the head and neck for leverage. The treatment utilizes, first of all, moist heat packs to the neck for muscle spasms to transiently increase local circulation.

Second, the use of a cervical traction device, such as over-the-door, or bed clamp-on traction devices, and with a weight bag. Water or sand is placed in the bag. The weight in the bag should be greater than the weight of the head. The weight of the head is normally seven to nine pounds. It is desirable to gradually increase the weight up to as much as  $\frac{1}{8}$  of body weight for 20 to 30 minutes once or twice a day. When the weight exceeds twice the skull weight, there will often be an uncomfortable pressure on the jaw and teeth and most individuals will not tolerate more than 16 to 20 pounds.

The third treatment mode is body weight reduction to 10 to 20% below norms for those with moderate to extensive muscle loss. In other words, when one loses muscle, one loses a lot of tissue, and the normal weight with that muscle tissue would be lower than the norm. I prefer for simplicity and reasonably well-balanced nutrition to recommend the methods of Nathan Pritikin.

Anti-inflammatory medications, Tylenol or Ibuprofen, or, as Dr. Maynard has alluded to, Motrin or Advil, in 200 to 400-milligram tablets can be taken with or after meals and at bedtime with milk.

Sleep with a thick but comfortable pillow when on the side, so that the head is in a straight line with the body. Many pillows are very soft, but the head drops to one side of the pillow, and accentuates some of the compression problems. I turn the pillow on the side instead of flat, and clear the shoulder. If one sleeps in a prone position, get rid of the pillow altogether. In the supine position, have the pillow flat or low, slightly flexing the neck.

The next treatment consideration is occasionally the use of a soft surgical collar or Philadelphia collar that may help, if muscle spasm is acute. All orthotic devices are a two-edged sword and can, by prolonged splinting, facilitate muscle weakness.

Degenerative changes in the shoulder are usually present in, first, the glenohumeral joint (the main shoulder joint articulation, the ball-and-socket of the shoulder) or secondarily, the acromioclavicular joint. The degenerative

process of the former is usually the result of weight-bearing, such as crutch walking, or of swinging transfers, such as wheelchair to bed, toilet, car, etc. This weight-bearing, for which the shoulder was never intended, may also produce many soft tissue complications, such as the rotator cuff syndromes with inflammation, bursitis, ruptured tendons, such as rupture of the supraspinatus tendon with attendant loss of range of motion, periarticular muscle spasm, and progressive disuse.

Prevention may require changing swinging transfers to sliding board transfers or modification of crutch walking techniques. Exercise, per se, is not the culprit, but rather the loading forces. Therefore, try to unload, and try to substitute. In spite of the destruction, I believe that non-resistive active exercise, such as swimming or wheelchair mini-marathon workouts where physical condition permits, are all desirable, as blood is brought to the joint by this activity and assists in repair.

It usually takes a period of 20 to 30 minutes of continuous exercise to be effective, and one must work through a certain amount of stiffness and pain. A preliminary stretch or workout is effective and often must be repeated at intervals during the workout, such as pendulum exercises.

If a more structured treatment program is necessary by a physical or occupational therapist, then I suggest short-wave diathermy or ultrasound, such as Dr. Maynard has alluded to, as the heat modality of choice for the shoulders, hips, and knees. These modalities will promote an increase of the deep circulation better than moist heat.

Many find sleeping on one side adds to pain; therefore, I have found that the double-pillow technique which I've mentioned is often beneficial here. Use of anti-inflammatory medications may also be of benefit in these conditions, and seems to be most effective when the pain is aggravated by a falling barometer. Many have noted that, and feel better when the barometer rises. That's physiologically sound, because of the intercellular-extracellular fluid compartment shift, and particularly among fibrous connective tissue which does not respond well to intercellular fluid changes.

With respect to degenerative changes in the acromioclavicular joint, there is probably little that is effective other than symptomatic relief through heat and anti-inflammatory agents. Often the destroyed joint will spontaneously fuse and stop the motion that created the pain. Fusion will reduce the range of motion in internal and external rotation of the shoulder in hyperflexion and hyperabduction. If, after time, the problem is not resolved, sometimes a resection or osteotomy may be considered, but then one may put up with a free-floating clavicle, at the distal outer end. Some find that a problem.

Notice that in Dr. Yarnell's statistics, as well as some of my own studies with Dr. Rawlings at the University of Western Australia (which we presented at the American Spinal Injury Association 1981), and finally by the studies of P.J.C. Nichols at the Nuffeld Orthopedic Hospital, and the Mary Marlboro Lodge of Oxford, England that problems of destructive changes in the elbow are almost non-existent. It is true that tardy ulnar palsy often exists, and Dr. Maynard and Dr. Yarnell referred to that, but one rarely finds degenerative changes in the elbow.

In the wrist and hand, there is occasionally destruction of the radial-ulnar joint, and occasionally of the small carpal joints like the navicular, the lunate, and the pisiform joints that provide that articulation of the wrist. However, the most frequent sign of destruction is the destruction between the metacarpal and the carpal joints at the thumb. This is frequently in wheelchair users who are pushing their own chairs, and it exists because of the repetitive hammering of the thenar eminence of the hand. It also produces a carpal tunnel syndrome. It is a major problem particularly in wheelchair athletes, and individuals who are very active in their wheelchairs.

The treatment and prevention are almost the same. Where extended activity is undertaken, use bicycle or sailing gloves. Bicycle gloves are cut off at the proximal interphalangeal joint; the sailing gloves are cut off at the distal interphalangeal joint. These gloves should be slightly too large, and one should insert a foam rubber pad, sorbothane, or other polyurethane gel pad, or artificial fat, such as Spence Gel, under the palmar side of the glove, and over the wrist and thenar eminence. This will often alleviate the problem.

A good joint protection program outlined by physical therapists is highly beneficial. Regional heat, such as a pan of hot water, or use of a paraffin bath, can also be helpful. Splinting of the interphalangeal joints, that is, in the fingers, with IP stabilizers will be helpful in many individuals, and of course, the medication situation previously described is applicable here.

In the lower extremities, the weakened, imbalanced musculature, and what I call "Indian" weight gains (weight gained that keeps creeping up on you), are responsible for hip, knee and ankle problems. If one has been accustomed to walking without aids, then resorting to their use will be highly beneficial. The cane or crutch should be used in the opposite hand to spare the repetitive trauma. Symptomatic relief may be partially afforded by moist or deep heat, as previously mentioned, as well as the use of anti-inflammatory agents.

I have found that in those individuals who also have concurrent low back pain, the use of inversion traction or gravity suspension traction is often quite beneficial. Orthotic use will also frequently transfer the forces from the hip or knee to the pelvis. One must use lightweight materials. With the new advances of orthotics in polypropylene and polyethylene, metal joints may sometimes be eliminated. However, one of the greatest problems here is the psyche. A person will often compensate for years without an orthotic device, and then an illness will force recumbency followed by inability to substitute any longer.

The recurvatum of the knee, or the back knee, is destructive and painful. Use of a knee cage brace is rarely a satisfactory solution. They often must be so tight that they occlude venous circulation. I believe that a knee-ankle-foot orthosis (that is, a long-leg brace), is preferable, as the forces are transferred to the ground and weight-bearing is partially relieved. This is also true of the hip (and I have often resorted to the prosthetic principle of a modified quadrilateral socket) with ischial weight-bearing in a knee-ankle-foot orthosis, or the use of an ischial ring. This permits the pelvis to sit on the rim, and reduces weight-bearing across both the hip and the knee.

One must never forget the wisdom of Dr. Robert Bennett of Warm Springs, Georgia, when he said the ideal brace should weigh nothing, cost nothing, and be invisible.

Many other considerations may be entertained, to include surgical joint replacement in the hip, knee, and shoulder in diminishing order. The post-surgical period may be a trying one, and one may find the recovery period immobilizing for the post-polio as compared with other relatively able-bodied persons.

The problem of scoliosis is so complex I cannot offer simple remedies. It requires the most careful scrutiny and guidance by orthopedic surgeons, physiatrists, physical therapists, and others. Use of selected asymmetric exercises may be initiated under the therapeutic supervision of these professionals. Orthotic devices and surgical fusion are frequently necessary. Use of heel lifts to compensate for pelvic tilt when the cause is leg length discrepancy, is often beneficial.

Pain in the lumbosacrum from degenerative disease, such as a facet syndrome, is aided by heat and some exercise. Most of all, I find pelvic traction with a halter, using up to  $\frac{1}{4}$  to  $\frac{1}{3}$  of body weight, is beneficial. Use of suspension, traction, or inversion traction is also often helpful. No one treatment is universally satisfactory. Many or all of the above remedies may be helpful.

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### **Thomas Gucker, 3rd, M.D.**

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It's been estimated most recently that the number of living polio people in the United States is 250,000-300,000. With this in mind, the results of several questionnaires conducted in the past three or four years has included less than 1,000 reporting. My plea, therefore, is to emphasize the vast majority of people who are still actively living and are not experiencing any truly new or significantly different findings (not symptoms such as alleged weakness, fatigue, soreness, tenderness, etc.).

In my experience over the past 45 years in treating polio patients and living it in my own life, I have realized several important findings.

Polio people are human beings. As such, and with advancing years, they are subject to the same symptoms and objective findings of abnormality that the usual human being experiences. It is very important, however, not to overreact to X-rays that may reveal a considerable amount of so-called degenerative arthritis of the spine, hips and knees. In my own experience, I have been impressed with the relatively less severe presence of these conditions, even in the involved lower extremities. One cannot interpret subjective complaints of pain, soreness and tenderness by attempting to read the findings of an X-ray.

Of great importance is the maintenance of flexibility and mobility of the body, especially the shoulders, entire spine, and lower extremities. Often polio people, who are limited in amounts of weight-bearing, spend most of the day in a wheelchair and as such tend to slump as they get more tired, compromising the physiology of the heart and lungs and reducing the circulation. The solution is "keep on fidgeting." Particularly in a wheelchair, it is advisable to do a push-up maneuver, elevating the buttocks and trunk at the shoulder level relieving the pressure on the buttocks, straightening the spine and increasing the space for the heart and lungs to function with improved circulation to all these organs in addition to the abdominal organs. The shoulder depressors and triceps elbow extensors are repeatedly exercised whenever this is done.

I am convinced that one can maintain an active, meaningful life. Even seriously deformed extremities can be properly supported by modern techniques available through orthotics and especially-made shoes.

It is my conclusion that polio's long-term history is a continuum from the acute stage to the end, and depending upon the amount of common sense and practical motivation the individual possesses, the rewards will be proportional.

# Recognition of Need for Respiratory Support

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## Ernest Johnson, M.D.

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When we breathe normally, the pressure inside the lung is negative and the pressure at the mouth is positive; therefore, air goes into the lungs. The pressure at the mouth normally (at sea level) is 760 millimeters of mercury. When the diaphragm descends, the pressure goes down three or four millimeters of mercury and the air rushes in.

When one uses a positive pressure ventilator, the pressure is fifteen millimeters of mercury or centimeters of water, and the air has a pressure gradient going in. One can see the difference between someone who breathes with the diaphragm descending creating the negative pressure inside the lung, and those individuals who depend on positive pressure by mouth. In the latter instance, the positive pressure gradient inside the chest impedes the return of venous blood to the right heart.

When one has poliomyelitis a long time, 25-30 years, one becomes aware that one is not sleeping well, is having nightmares, and blood gas studies show retention of carbon dioxide. One may need the next level of ventilation assistance. Maybe one is on a rocking bed and one needs to go to the chest-abdomen cuirass. Maybe one gets along fairly well during the day, but when lying down at night, one can't go to sleep and needs a rocking bed to assist with ventilation. In the usual circumstance, vital capacity is reduced about five percent in the supine position due to more venous blood in the lungs.

Post-polios who used a ventilator during their acute phase, but not since, may have reduced their pulmonary thoracic compliance through gradual stiffness and aging of the chest wall and lungs. This occurs because polio persons can't take a deep breath (sigh).

Sighing takes a great deal of air into the lung and stretches the lungs. If the pulmonary and thoracic compliance (usually  $\frac{2}{3}$  related to stiffness of the lung, and  $\frac{1}{3}$  to the chest wall) requires more work to breathe, it takes a greater pressure to enlarge the chest cavity than it did before. This happens after 15-20 years of breathing without periodically (every hour or so) stretching the lungs.

I treated an architect in Lima, Ohio, about twenty years after his acute polio. He was found to pass out periodically during the day while working at his desk. After a thorough neurologic work-up, we found he was retaining carbon dioxide, and additional ventilation assistance brought his demeanor up to "lively." He uses positive pressure during the day and a plastic wrap at night.

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## D. Armin Fischer, M.D.

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How do post-polio people know when they are getting into trouble with breathing? For most people, shortness of breath is the *sine qua non* of this kind of trouble. However, many times breathing problems can be more insidious in individuals whose breathing muscles are limited. One does not always go into respiratory failure suddenly. The respiratory problem may develop very gradually.

My experience at Rancho indicates that people who go back to respirators 20 or 30 years after the acute episode are generally those who were using respirators at the onset of their polio and had respiratory muscle involvement. The major exception to this is the individual who developed chest deformities: kyphoscoliosis. The individual with kyphoscoliosis does develop respiratory failure, but on a different basis from the individual who has muscle weakness. Kyphoscoliotics develop respiratory failure because the deformity of the chest does not allow them to exchange air evenly. They get low oxygen levels in the blood which, over a long period of time, produces an increase in the blood pressure in the lung. Increased blood pressure puts a strain on the heart resulting in failure of the right ventricle and this results in failure of this side of the heart, producing fluid retention.

In regard to the question from the morning session, "Does polio have anything to do with the heart?", the answer is "yes", but indirectly. We don't generally see degenerative heart disease due to polio, but cor pulmonale (pulmonary heart disease) in people with chest deformities can develop.

People return to the use of respirators after an acute event of some kind. Usually they've already had damage to their breathing muscles and they don't have an effective breathing reserve. The breathing reserve gradually decreases just as it does for everyone. We all lose a certain amount of vital capacity with aging, but if one starts out with a low vital capacity following the initial insult with polio, and then loses a normal amount of breathing volume over the years, one can get to a marginal level. It doesn't take very much to tip one over that margin.

When the vital capacity is under 1 liter (under 1,000 cc's), particularly under 700 cc's, a chest cold can result in respiratory failure. The carbon dioxide will rise, and the oxygen level in the blood will fall. In most cases, this will require hospitalization and intervention to support respiration. Occasionally a post-polio person who goes to an acute hospital unit under these circumstances ends up with a tube inserted in the trachea, and sometimes a tracheostomy. If one goes to a hospital which still has tanks and cuirasses and rocking beds, there is a possibility one



can temporize about the need for tracheostomy. It is important for post-polio people to follow their vital capacity so they can anticipate future problems and actively participate in decisions.

What does daytime sleepiness mean? Is that an early signal or a late signal? It means one didn't get a good night's sleep usually, and there are many reasons for that. It isn't always just because of carbon dioxide retention. As a matter of fact, in my experience, an acute episode of respiratory insufficiency usually develops with an acute infection or chest injury, and the body doesn't have time to compensate for it.

Measurement of carbon dioxide is very important because if it is rising, it is an important risk factor. More institutions should use the rebreathe technique for measuring carbon dioxide rather than the routinely used arterial blood gas studies. Sleepiness during the day in most cases is because of poor sleeping rather than carbon dioxide retention. Many post-polio people may have what is called sleep apnea or obstructive sleep apnea. The individual with this problem may not be aware of it, but a spouse may notice that they snore and sometimes stop breathing. This sort of problem is being discovered more and more with post-polios. These problems can be due both to the obstruction with loose throat muscles, but also due to problems with the central breathing drive.

In summary, post-polio people need to have regular followups, particularly if they have marginal respiratory reserve. There is a need to follow vital capacities and also carbon dioxide levels. Sometimes, if the vital capacity drops below 1,000 cc's, consideration of the use of rocking beds, cuirasses, and mouth positive pressure can help in preventing or delaying respiratory failure.

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## Augusta Alba, M.D.

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If one knows one's pattern of muscle weakness, it will help to determine whether or not one is a candidate for needing a ventilator. Remember that the diaphragm, which is the major muscle that is used mainly in sleep, is innervated at the same level as the neck, so if there is any significant degree of neck weakness, one may, by inference, have a significant degree of diaphragmatic weakness as well. This is something that should be checked out with a physician.

The same thing is true if there is weakness at the shoulder girdle where the muscles of the shoulder girdle are innervated at the same levels that the muscles of the ribcage (which are used for breathing) are innervated. If there is weakness of the shoulder girdles, that, too, should be checked to determine whether or not there is weakness of the respiratory muscles.

One can tell very easily whether or not abdominal muscles are weak simply by making an effort to cough. I usually have people grade their own cough in poor, trace, good or normal, similar to manual muscle testing.

If one has little ability to cough, then that's another group of muscles that aren't doing the job. This may not trouble ordinary breathing during the day, but will make the difference as to whether or not one will need a res-

pirator when there is a respiratory infection because of an inability to cough. Recognizing those major groups of muscles will help in determining whether one should see someone familiar with pulmonary functions.

With daytime sleepiness, I want to remind anyone needing help in diagnosis that there are more than 70 certified sleep centers throughout the United States today into which one can be enrolled, spend a night, and determine whether one has a form of central or obstructive apnea, mixed apneas, or hypopneas, or some throat weakness.

If there has been a problem of swallowing earlier in polio, one may end up with a throat weakness later on, and that may contribute to an obstructive apnea. If one uses accessory muscles during the day for breathing, they have very little automatic function.

Now we are performing a tracheostomy as a bypass procedure if obstructive apnea is found. We also use what is known as CPAP which is just an air pressure on the nose to open the posterior pharynx so that it is easier to breathe through. The very latest thing is a pharyngopalatouvuloplasty which means we pinch out the tissue in the back of the throat and the nasopharynx for a freer airway.

I just advised a gentleman from California to be extremely careful of that procedure because he may lose his considerable ability to frog breathe, due to leakage if we pinch out too much tissue. This is something a post-polio physician should know.

Anyone over 65 is considered to be a poor risk in the anesthesia world, and if polio is added on top of that, it makes even a greater risk. Surgery, even without general anesthesia, may be a risk; long, exhausting trips may just tilt the scales in favor of the muscles being too tired to ventilate well. The position one finds oneself in may not require a ventilator as Dr. Fischer pointed out, but in another it might. The constriction of a corset may play a role. A good abdominal support is great, but if it is so tight one can't breathe, one is literally restricting whatever muscle is left.

Any infection with a temperature increase may lead to a need for ventilatory support. The latest thing in the area of weaning from a respirator (maybe it's only needed temporarily) is Pulmocare, a high-fat type of nutrition which allows one to have a lower metabolism and therefore get off the ventilator a little more rapidly.

Certain drugs, such as antibiotics and anesthetics, muscle relaxants, tranquilizers, and of course, alcohol, can increase your need for ventilator support.

We've talked about aging, and there are two aspects there. We already talked about the vital capacity. The other aspect is diffusion. How rapidly can the oxygen get into the bloodstream? Unfortunately, by the time we're 70, that ability is about half of what it was when we were younger. It drops by another 25% every decade. I tell people that by 80 or 90, they have a problem with or without polio.

There are other types of respiratory support which include chest physical therapy (all of you should know a good chest physical therapist in the community). The techniques of postural drainage and of chest physical therapy should be taught to a significant other in your life, and within the near future, we'll have a new cofflator to help in this area.



I would like to caution everyone to take the pneumococcal vaccine and the flu vaccine so one doesn't end up with intrinsic lung disease, such as from acute pneumonias.

Today, there's a great deal more attention in the area of chronic obstructive pulmonary disease (COPD) paid to muscles. Before, it was simply the lungs, but now we've found that a major reason for a COPD patient going into respiratory failure is overwork. A person with COPD has apparently normal muscles, but they can't work as hard as they have to in order to breathe the person successfully. This theory is being studied intensively by pulmonology research workers, and what they learn there about the fatigue of respiratory muscles will help us to understand the weakened diaphragm better.

It is known that even the normal diaphragm, by the time it is working at 15 to 20% of its maximum function, will already undergo fatigue if it has to do this on a prolonged basis. At 40%, it's going to fatigue very rapidly, and the circulation to the diaphragm plateaus at 40% of maxi-

mum function. It doesn't get any better even though one decides to use 50 or 80% of the diaphragm at any one time.

The COPD patient is encouraged to do what we've suggested to people with weakened muscles: sleep with a ventilator at night. Rest the muscles so they work better during the day because they've gotten a chance to rejuvenate.

Because of the decreased compliance that Dr. Johnson described, the work of breathing will be greater with weakened muscles, and that may be another reason why one might need to use a ventilator. Everyone should know that one of the primary causes of COPD is smoking. I just spoke to one patient who, three years ago, was slated to die on his next bout of respiratory failure. He stopped smoking after he heard that, and he's been doing great since. He hasn't had another bout of acute bronchitis, so it's important not to compound the problem with smoking.

## Questions & Answers

**QUESTION:** *What can each of us do to maintain maximum pulmonary thoracic compliance?*

**DR. ALBA:** Glossopharyngeal breathing (frog breathing) is an excellent way to stretch the chest cage and lungs.

**DR. JOHNSON:** Another way is to take deep breaths with positive pressure ventilation.

**QUESTION:** *What are the dangers of tracheostomies?*

**DR. FISCHER:** Tracheostomies, like any other surgical procedure, have a certain amount of risk, particularly when performed during an emergency. At that time, the risk/benefit is usually considered and taken from that point. In the immediate postsurgical phases, there is always some risk, small, but some, that there may be bleeding. After the tracheostomy, there may be complications. Occasionally, the trachea narrows due to irritation of the tracheostomy tube. This usually takes a long period of time, and rarely occurs to a significant degree to require any intervention. Most people have trouble with occasionally getting granulation tissue around the trach which may need to be cauterized.

**DR. JOHNSON:** Rarely, a connection (fistula) can occur between esophagus and trachea.

**QUESTION:** *What about infection?*

**DR. FISCHER:** In the acute, postoperative phase, this is uncommon, but these are open tissues and if appropriate care isn't taken until that all heals and granulates in, there is a risk of some infections. Later, people may occasionally get inflammatory changes around the stoma.

**QUESTION:** *Is humidification necessary to prevent tracheal bronchitis?*

**DR. FISCHER:** Not always. Certainly in the early days when trachs were done, there was no humidification. More squamous membrane develops within the trachea. It's the acute emergency intensive care unit doctors who like to put everyone on humidification. With chronic trachs, one does not have to have humidification.

**QUESTION:** *What about hypoventilation caused from cuff leaks?*

**DR. FISCHER:** In special circumstances when people require ventilation at night, cuffs may be used to prevent underventilation when the patient loses excessive air through the mouth when asleep. This problem is usually associated with increased stiffness of the lungs or the chest wall. The problem is usually compensated by increasing the volume if one is using a volume ventilator. It occasionally may be corrected by using a pressure-limited ventilator. These problems usually require in-hospital evaluation to determine the appropriate management.

# Psychological Adaptation to Changing Respiratory Support

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**Hugh Newton-John, M.D., F.R.A.C.P.**

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For post-polios, change frequently means loss. This may be loss of mobility or of independence, loss of function, or even loss of beauty. Such losses can be devastating, and mean grief and an uncertain future. Whilst post-polios have an extraordinary propensity to overcome what, to many others, would seem insuperable obstacles to living, they do suffer from changes, including changes to their life support systems.

Some psychological adaptations take place when a post-polio is faced with a need to change his or her ventilator. I am assuming that we are considering only those post-polios who know they have respiratory muscle weakness, and are already using ventilatory support.

A major change such as a new ventilator raises many expectations. Sometimes (for many possible reasons) these expectations are unrealistic. One of the problems with introducing a new system to post-polios is that if expectations are unrealistic, the new system may fail, not for mechanical reasons, but simply because it is not acceptable psychologically. Of course, the new system may not have been chosen appropriately in the first place.

The major medical reason for wanting to change a ventilator system is that the old system is not doing the job properly. From the clinical viewpoint, this is usually manifested by a reappearance of symptoms such as daytime fatigue, headaches, loss of energy, and loss of concentration. While all of these could be due to other factors, often they are signs that a change is needed. A simple explanation for these symptoms is that the machine may need maintenance. Several of my clients have come along wanting a new ventilator, but when we checked their old tank respirator we found that it was leaking badly. Once the machine was repaired everything was fine.

Most commonly, however, recurrence of old symptoms means that the body is changing. This is the most important reason why a new ventilator is needed. Deterioration in muscle strength, of course, involves not only the limb muscles, but also the respiratory muscles which deteriorate with age, particularly if there is an increasing deformity of the spine.

There are several other important medical causes of bodily change. One of these is obesity. If a person is overweight, it is more difficult for the ventilator to do its job. Fortunately, this is correctible. Sleep apnea has recently been shown to be common in post-polios, and may be the main reason for a change to a new system. Finally, any deterioration in respiratory function — whatever its cause — may be further worsened by heart failure.

There are several ways of dealing with these physical changes. The first is to change to a new ventilator system.

One may exchange a cuirass for an iron lung. Incidentally, iron lungs are known as "tanks" in Australia, and they're made of plywood rather than metal. Another approach may be a tracheostomy. A new system recently developed in Australia is called "nasal CPAP." This is a device involving an air blower and nose-mask designed to help people with sleep apnea. Another change could be to begin using positive pressure ventilation by mouth during the day or to spend more time with the old system, for example, by using the iron lung every night instead of every second or third night.

Before any such changes are made, it is important to have a full medical work-up. A correct medical diagnosis is imperative, or inappropriate treatment may be prescribed. The diagnostic work-up may need to include a sleep study to detect sleep apnea.

Once all this has been done, the post-polio will be faced with a potential change to his or her lifestyle. First reactions to such a change vary a great deal. I have grouped people's reactions into four identifiable responses.

The first of these is an enthusiastic "Whoopie! Let's have two of them." The second response is "Mommy, I want one too." This is the response of post-polios who may feel insecure and fear that unless they keep up with the Joneses they will somehow be left behind.

Another common initial reaction is "Don't call me, I'll call you." Denial that there is a problem (burying one's head in the sand) is one of the commonest reactions to an unpleasant event.

Finally, a post-polio may respond with "Doctor, I'd rather die." While this may be realistic in some circumstances, it more often implies a deep fear of the unknown or a very strong prejudice against certain types of intervention.

Let us look at these responses more carefully. People who come out with an enthusiastic "Whoopie! I want two" response are good fun. Such people are prepared to try anything, and I find that when I have a new and untried system they are just the people who will volunteer to test it. However, it's very important through counselling to prevent unrealistic expectations building up and so avoid a big let-down later on. Adequate explanation before any change is contemplated is essential, particularly before a procedure like a tracheostomy.

The second reaction I described was "Mommy, I want one too." This reflects a fear of being left out or left behind. If a friend has a new ventilator, it is easy for one to feel envious and to demand "equal rights," even if there are no clear-cut medical reasons for a new system. In Australia, ventilators are very expensive, especially positive pressure machines such as the LP-3 or LP-4, which cost around (A) \$9,000. (The Australian dollar has depreciated re-

cently and these machines are imported from the U.S.A.) We have only in the last six months had an agency for these ventilators in Australia. Because I have had to be selective (for medical and financial reasons) about who comes first, it is important for me to spend time explaining these factors to people who may feel discriminated against.

The third reaction was that of putting off having to make a decision. "Well, I'll just think about it, doctor. Perhaps not today, perhaps next week, next year or maybe never." The underlying hope is that, by not admitting to oneself that things are getting worse, they won't get worse. This denial mechanism is very strong in some people, who resist all "rational" arguments to the contrary. It's no use reminding them that their lips are going blue or their legs are swelling up. These people need gentle handling and lots and lots of talking and reassurance. Sometimes it helps to introduce them to others who have been through a similar change in respiratory support. Eventually, many will change their attitude. However, some of their expressed concerns may indeed be realistic. They may tell you they don't want to look ugly; they don't want something sticking out of their throats, and that's fair enough. They don't want to lose their independence, and that's realistic. They're legitimately worried about restriction of mobility and inability to speak normally. I also think that a powerful influence is the fear of dying, which makes it even harder to accept change.

This brings us to the last reaction which is, "I'd rather die than have a change." This may be a rational decision by a responsible adult, and one must respect such decisions. It may be related, on the other hand, to having seen somebody else die after a tracheostomy. But most often, "I'd rather die" means fear and lack of understanding of the consequences of change. Often these frightened people do change their minds when they finally realize that they are in fact in the process of dying. As they realize they have reached that stage, they often make up their minds, and when they do, it may be with a sense of urgency: "Hurry up, Doctor, do it now. Don't wait. I don't want to think about it any more."

Sometimes the change in attitude I have just alluded to may be accomplished only by the development of unrealistic expectations. I had a patient called Suzanne, who had been in an iron lung on and off, mainly at night, for the last 20 years, and recently developed sleep apnea and needed a tracheostomy. She had developed heart failure, she did realize that she was getting worse, but she refused to have a tracheostomy, saying literally, "I'd rather die."

Finally she agreed to the tracheostomy. It cured her headache and her bloating, the blueness in her lips disappeared, her swollen ankles went down, and she lost her fatigue. Yet she's still grumbling twelve months after the operation that she can't take a deep breath. She **never** could take a deep breath, and I think that she expected some sort of magic out of this operation that would make her able to take a deep breath once more, as she did 40 years ago. This was an unrealistic expectation of the procedure. Suzanne does have some legitimate grievances. For example, she's dependent on others for suction because she can't use her hands very well, and she is dependent on others to connect her up to the ventilator. She blames me

for those things, I suspect, and I feel that perhaps I should have spent more time in explanation before she had the operation.

Finally, there are very important positive aspects of changing ventilatory support. People do feel better. If the right diagnosis has been made the improvement is sometimes dramatic. You may be able to sleep in a real bed, perhaps with your sexual partner. You may find you can undertake activities that you hadn't been able to for ages. Finally, you realize that you weren't dying after all.

In summary, change should be positive, expectations should be realistic, and one should understand the processes in the body which have led to the need for change. Most importantly, the doctor and the ventilator user must always respect each other's point of view.

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### Joseph Kaufert, Ph.D.

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One unique feature of all three of the conferences sponsored by G.I.N.I. has been the bringing together of information about individual consumers' personal experience with polio-related effects and information from epidemiological surveys or clinical follow-up studies of representative samples. Follow-up surveys, such as those carried out at Rochester, Houston, and Manitoba provide an indication of the incidence and severity of the late effects of poliomyelitis.

However, epidemiological surveys cannot deal with issues of personal meaning associated with changes in functional status, nor can they adequately document the wide range of personal coping strategies which have evolved over the years. Questionnaires also cannot adequately deal with the influences of changes in life support technology and changes in public policy which have influenced the availability of technology.

In order to link survey data on respirator-dependent people with more in-depth descriptions of consumer experience, my colleague, Dr. David Locker, and I conducted extended, open-ended interviews with a subsample of people currently using mechanical ventilators. Respondents were selected from the sample of 186 people who initially required mechanical ventilation during the major polio epidemics in Manitoba in 1950-58. We were able to use the epidemiological survey to identify ten people who had thirty or more years of experience using respiratory equipment and who had recently experienced changes in dependence upon mechanical ventilation.

Interviews were conducted over a six-month period and included tape recorded life histories documenting: (1) people's recollection of acute care respiratory support experience; (2) description of initial rehabilitation and attempts to minimize dependence upon mechanical support equipment; (3) descriptions of later experience of respiratory insufficiency; (4) experience with changing respiratory support technology and (5) descriptions of social and psychological adaptations to daily living.

The in-depth interviews revealed that newer forms of mechanical respiratory support enhance the quality of everyday living by improving energy levels, promoting feelings of well being, and allowing for more intensive

mobility in the community. Modern ventilation technology was perceived as a resource, incorporating it into the strategies and routines developed to cope with the problems of everyday living; in this case, managing respiratory insufficiency and maintaining an adequate oxygen supply. At the same time people had to develop a new set of strategies and routines to cope with the machine, its associated hardware, and its technical limitations.

Several of the respondents emphasized that, while they had achieved important gains from the use of improved respiratory technology, such as positive pressure machines, there were also losses. In developing coping strategies people had to balance the benefits and costs in the course of daily life. They had to adapt to the idiosyncracies of the machines they used, find ways of maximizing the benefits derived from them, and develop a repertory of coping skills in order to manage the problems these technologies involved.

At a minimum, respirator users, or more usually their close associates, developed those technical skills necessary to connect, disconnect, and monitor the functioning of machines. In this way, new technology not only impacted on the quality of everyday living, but also radically transformed its character.

In the interviews, people outlined primary psychosocial strategies including trading-off, selective allocation, pacing, and short-cutting. Trading-off involved reorganizing daily living to maximize the advantages and minimize the disadvantages of mechanical methods of respiratory support. Selective allocation involved using one's limited reserves of time or energy to accomplish a small number of valued or necessary activities. An example of this response was described by a woman who had recently made the transition from an iron lung to a portable ventilator. Before the transition she would spend most of the day resting in the iron lung in order to conserve energy to spend time with family and friends in the evenings. Having exchanged her iron lung for a portable positive pressure unit this strategy became redundant. Substantially improved energy levels and freedom from the need to concentrate on breathing meant that she no longer had to be as concerned with selective allocation.

Pacing involves learning what activities can be undertaken, for how long, and how often, given the limited resources the person has available. This strategy was most evident in the daily routines which characterized the lives of the majority of the respondents. One woman said that she tired easily but over the years, "I've learned to pace myself. I stick to a definite routine and try not to get overtired as it takes me a long time to bounce back."

Short-cutting is also a process that finds ways of performing the activities of daily living with the minimum of effort. This is not simply a matter of coping with physical disability, but also one of preserving a limited energy supply; less effort means using less energy. For example, one of the respondents explained how she used the motion of the rocking bed to assist in moving her arms. If she decided to read, she would always sit on the rocking bed where turning the pages of her book could be almost wholly accomplished by the movement of the machine. These day-to-day coping strategies provide some insight into the psychological and social adaptive strategies which

facilitate adaptation to long-term mechanical ventilation. However, other factors such as unanticipated aging effects and changes in the availability of compensating services must also be considered.

The occurrence of late post-polio aging effects raises new uncertainty and the fear that any deterioration in physical or respiratory function will threaten the adaptation of those who have been able to live in the community. The implications and consequences of such deterioration, should it occur, are dependent upon a number of contextual influences.

The development of community support services, such as the respiratory home care program, has buffered many of the negative outcomes associated with increasing need for ventilation. However, several respondents emphasized that limitations of respiratory home care benefits, such as those proposed last year by the Reagan administration, would seriously limit their ability to continue to live independently in the community.

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### **Adolf Ratzka, Ph.D.**

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I got polio in 1961, and two days after the onset, I was put in an iron lung. Six weeks after that, I started to breathe on my own for about four minutes, and gradually increased that period by daily training, minute by minute.

Three months after the onset of polio, I was able to leave the iron lung, and, as they say, graduate to the rocking bed which I used each night until 1966. In 1966, I made the move to the cuirass. The cuirass I had for a long time. In 1978, I started experimenting with positive pressure through the nose via a face mask. The period of experimentation ended in May, 1984. Since then I have not used the cuirass any more and I use my face mask only.

Moving from iron lung at night to the rocking bed had definite advantages. People looked at me as more normal. I felt more normal, too. People could touch me. I was more independent and I could do more things for myself.

Why did I exchange the rocking bed for the cuirass? I had received a scholarship and wanted to move from West Germany to the United States to attend college. There would have been no room for a rocking bed at the dormitory, so I had to give it up and try something else. I had not had much exposure to the cuirass before; nobody at the hospital in Munich had one, but it worked fine for a number of years.

What was the reason, then, for experimenting with positive pressure? The cuirass, I strongly believe, had reduced my chest capacity. As the years went by, I felt that my margins were getting smaller and smaller. With the cuirass, for example, eating late meals meant no sleep for several hours. After some years, I used to run the Monaghan 170C at maximum pressure all the time. A more powerful machine would not have presented a lasting solution either, because the "rib crushing" effect of the cuirass would have been even more powerful and would have accelerated my loss of vital capacity.

It is difficult to travel when you have to haul a rocking bed along. A cuirass, on the other hand, is a marked improvement, especially when travelling by car. When it comes to air travel though, the delicate shell of the cuirass

cannot be put with the other luggage. By the time I was really getting into air travel, a positive pressure machine offered a lot more mobility. It is smaller, lighter, needs very little current and can run on the wheelchair battery for many hours.

Positive pressure presented a much more effective means of ventilation than the cuirass and it enables me to use respiratory support during the day. Having access to respiratory support during the day has become more important for me as I get older and as my workload increases. Positive pressure has even improved my social life. Have you noticed that those of us who have breathing problems are usually quiet when we eat? We have a hard enough time as it is getting our meal down, while everybody around us eats and talks. For many years I mistakenly thought that this silence of mine was just an expression of being a lousy dinner conversationalist until it occurred to me that I conserve my energy by concentrating on eating. It also helps in avoiding getting food down the wrong throat which can be a pretty scary experience for you and your company. The more I eat, the less air I have for speaking. For the rest of mankind, the opposite seems to be true: the more they eat — and especially — drink, the louder and merrier they get. Under these circumstances, talking — for me — is a very tiring effort, and I devote my energies to the essentials and enjoy my meal. Using mouth positive pressure after a heavy meal changed my image, because when I fill my lungs with air, I can speak up, people listen, and I find myself a creative speaker.

All my changes in respiratory support had for me a positive meaning. Unlike Dr. Newton-John, I do not feel that I lost something. In fact, in most of these changes I came ahead on two counts — I gained more mobility and a more efficient way of ventilation.

How about changes where one of these conditions is missing, where the change would lead to reduced independence, like moving back into the iron lung? That will not happen to me because in Sweden there are no iron lungs anymore. If I get a bad case of pneumonia and my positive pressure equipment is not sufficient, I might have to consider a tracheostomy. I must admit that a large part of my motivation behind experimenting with face masks derives from the fact that I'm afraid of a tracheostomy.

On the other hand, I also know that I want to live, and given the choice between dying or having a tracheostomy, I'd certainly opt for the latter. I know enough people who continue to live active lives despite a tracheostomy, or maybe I should say, because of a tracheostomy. Such positive role models may be the best help in overcoming one's resistance to any change. Whenever one is contemplating a new breathing method, one should seek out the people who make the best of it.

It is also important here not to confuse cause and effect. For a lot of people the device or the new breathing method that they need takes on a symbolic value and they fight it as if it was the cause of their condition, whereas, in fact, it is an instrument to alleviate their condition.

Our capacity to adjust to changing circumstances is enormous. What we have to keep in mind is that regardless of the equipment we use, we are still the same person. People around us will respect and love us for what we are, not for what type of machine we happen to use.

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## Valerie Brew Parrish

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The polio conferences which have been held since 1981 have successfully sought to educate polio survivors about the potential need for additional respiratory support. Physicians participating at this conference have once again painstakingly elaborated on the warning signals that indicate the need for increased ventilation.

The unequivocal realization that additional ventilation is required can be quite traumatic psychologically. The polio survivor has been forced to come to grips and cope with a disabling condition as a result of the initial onslaught of the polio virus. Now, decades after the virus first infiltrated its prey leaving behind damaged anterior horn cells... "Whamo!", the polio survivor may once again have to deal with what appears to be another attack.

The symptoms are subtle at first. A person may feel general fatigue, tired muscles, and morning headaches. It is easy to rationalize that these symptoms are simply from too much exertion or overwork. There is a real reluctance to confront the reality that the time has come to consider the possibility of using auxiliary mechanical ventilation.

I became a polio survivor in the year 1956. Like so many others, I was entombed in the iron lung, commonly referred to as "the tank." I was soon removed from the confines of the lung and transferred to the topsy-turvy world of the rocking bed. The memories of mechanical respiratory support diminished to the far corners of my mind as the years slipped on by without the need of such equipment to sustain me.

In 1981 I became pregnant. As my abdomen swelled, I found it increasingly difficult to breathe. Dr. Allen Goldberg, a physician at Children's Memorial Hospital in Chicago, prescribed a Zephyr Blower positive pressure ventilator for me. I used the ventilator all during my labor and intermittently throughout the ensuing years, especially during the hot and humid weather. I did not need to use the ventilator every day.

Then in the fall of 1984, my robust good health disappeared. I contracted every strain of virus and bacterial infection that polluted the air. I became extremely weak and fatigued. Each new infection was zapping my strength so that I had no reserve to combat the germs that were invading my body. The doctor that I was seeing thought I had a classic case of mononucleosis. Diagnostic tests proved otherwise. I sought the help of a pulmonary specialist who assured me that my skin coloring was too good to indicate any severe respiratory distress.

I had attended all of the previous polio conferences and I was aware of the warning signs that pointed to respiratory insufficiency and I knew that I was experiencing them. My heart would race and beat very hard. I woke up each morning with a headache which meant I had a carbon dioxide build-up. Although I was always exhausted, I couldn't sleep. When I did fall asleep, I was plagued by bizarre nightmares. My husband's cheerful "Good morning" greeting, became a concerned, "Good morning, how's your head today?"

I wrote Gini Laurie, the world's expert on polio-related problems. She recommended that I see Dr. Oscar Schwartz, a pulmonary specialist at St. Mary's Hospital in

St. Louis. When Dr. Schwartz suggested that I needed to be hospitalized for a series of complete vital capacity tests, I was terrified. I could not bear the thought of being cooped up in a hospital again. Furthermore, I did not have anyone nearby that I could ask to watch my daughter Tara.

Dr. Schwartz was not so easily put off. He can literally move mountains if the need calls for it. I was hospitalized in a private room which I shared with my husband and my three-year-old daughter. Any qualms that I had felt about being hospitalized soon vanished as I was placed under the competent care of Dr. Schwartz and his caring staff.

The array of medical tests were all-inclusive and I was soon introduced to a variety of mouthpieces to be used with a new ventilator, the PLV-100. Dr. Schwartz became a frequent visitor to a local scuba shop in his attempt to locate a suitable mouthpiece for me. I despised my mouth being covered up as I sucked the air from the mouthpiece. I worried that I would never be able to use the ventilator that I now required at night.

After being discharged from the hospital, I checked into a nearby motel. Dr. Schwartz wanted me to become familiar and comfortable with the new ventilator before I returned home to Carbondale. A respiratory therapist came to the motel to monitor my sleep as I breathed with the PLV-100. The therapist readjusted the settings of the ventilator and for the first time I started to feel comfortable with my machine. I drifted off into a very restful sleep.

I now use the ventilator every night. At first, I had to learn how to physically manipulate the mouthpiece so

that I would be able to take it off if I wanted to communicate. The most difficult problem that I had with my ventilator was that for some inexplicable reason, it caused my sinuses to back up. In the mornings I would wake up to find both of my eyes glued shut with liquid. It was frightening.

I began to wake up with massive headaches not from CO<sub>2</sub>, but from the ventilator triggering my sinus areas. I now had my choice of headaches. I could decide not to use the ventilator and have a CO<sub>2</sub> headache which was a nuisance but tolerable, or I could use the ventilator and have a headache that was so painful I would be in agony for days. I decided that it was better not to use my ventilator.

Dr. Schwartz suggested that I should take an Actifed and Sudafed pill which stopped the liquid build-up in my eyes, but I was still getting the terrible headaches. I was extremely discouraged. I knew I needed the ventilator but those headaches were excruciating. Now I am taking a prescription drug called Naldecon which has alleviated my sinus problem. I can once again use the ventilator and for the first time in years I am totally headache free.

The ventilator has made me stronger and I now feel I have finally regained my good health. The quality of my life has greatly improved. I do not fatigue so easily anymore. I can even once again play my harmonica. I am eternally grateful to all of those people who supported me and who endured my struggle to find a workable and lasting solution to both my headache and my breathing difficulties.

## Questions & Answers

**QUESTION:** *What is the most efficient form of mechanical ventilation?*

**DR. JOHNSON:** Since we have discussed the level of ventilator assistance from the various devices, I should emphasize that the tank, or the iron lung, is 100% efficient; as is positive pressure by mouth 100%. The chest-abdomen cuirass is 60%; the plastic wrap, depending on the pump you have working, is somewhere in between, 50%; the chest-only cuirass and the rocking bed are about the same, 40%. It has been shown on numerous occasions that the rocking bed will duplicate the ventilation efficiency of the tank respirator at 12 centimeters of water negative pressure.

Volume ventilators deliver a set of volume of air whereas the pressure ventilators deliver air at a set pressure. In the latter situation, secretions may increase the resistance to air flow to the point that the necessary volume of air is not delivered.

**QUESTION:** *I am Sunny Weingarten. I know what Adolf Ratzka has gone through over the years. Psychological problems with respiratory users are a serious problem. I've used an iron lung for 35 years, my portable fiberglass lung the last nine years. Polio people are very stubborn. I'm able to run a business from inside the iron lung, play the steel guitar, read four or five hours a day, operate the TV and VCR. One person told me that I accomplish more in an eight-hour day in the iron lung than he does in his office. What is the best way to convince an individual that one can adapt, like I have, to the iron lung or portable lung? What can we do to keep the psychological barrier down?*

**DR. RATZKA:** What helped me to use the LP-3 was the 1981 conference in Chicago. Seeing so many people on respirators humming and puffing and sipping and sighing made me think, "Wow! My God! If Sunny can give guitar lessons and fly the airplane with his partner with his LP-3, then I could do it too."

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# Workshop on Intermittent Mouth Positive Pressure

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by Augusta Alba, M.D.

The forms of positive pressure on the airway could be at the trach, mouth, or nose. It could be an entire face mask. Some of us are experimenting with just using the nose by itself to give positive pressure. IPPV is intermittent positive pressure ventilation, with an "M" before it for mouth, a "T" before it for trach, or an "N" before it for nose.

Volume and pressure console respirators are the kinds that used in an ICU. Some people even use them at home because they are such reliable machines to use than the portable ones. The portable ones are becoming more reliable. There are the LP-5, the PLV-100, and the BEAR 33 with about 10 different patient alarms.

The volume and pressure compacts are all positive pressure. They're volume or pressure-regulated, and provide a fixed rate, but in some of the newer ones one can assist that rate so one can get more than what the machine is set for. With all of them, one can add intermittent mandatory ventilation (IMV), which is a means of gradually getting off the respirator. One gets a breath from the machine and sets six or more, but then one can take more air from the room itself. Gradually one reduces the amount the machine is giving and adds more that one is giving oneself.

A manual resuscitator ventilator performs the same function as the machine, but it's done by squeezing a bag. Mouth-to-mouth, mouth-to-nose, or mouth-to-trach — one doesn't need to know CPR to know one can blow on a trach tube and breathe the individual (trach intermittent positive pressure), with one's own breath, because that breath has enough oxygen to sustain the other person's life. On a baby, use the nose and the mouth together. In the adult, use the mouth and close off the nose.

The cofflator gives a big breath in, so that part of it is positive pressure on the airway. The cofflator then switches to negative pressure, and sucks the air and mucus out of the lungs. One can do the same thing in the iron lung, but it's not a good cough. One needs seven liters per second of air flow in order to get a good cough, and this machine was designed for that purpose. There are only a few around the country since the last ones were built in the 1960s, and now Thompson is in the process of building a new one.

The pneumo-belt can be used during the day on the body, and at night one can use positive pressure on the mouth, or on the trach. If one doesn't have a belly which is moveable, the pneumo-belt won't work. One has to have enough tissue to push on for it to give any kind of tidal volume, but one is working with a very small amount of air to begin with, so one needs a very small tidal for it to work well. If one needs a large tidal because of diseased lungs, then the pneumo-belt won't work.

Glossopharyngeal breathing can be reversed. I've only seen one person who can do it, and it's not used for breathing, it's used for suctioning the airway. Once one goes to a trach, one no longer can frog breathe effectively because the air that is pushing down would go out of the

tracheostomy tube on expiration. It would be much less effective. If one uses mouth positive pressure on the same pressure that the machine is set or the same volume, one can take two or three breaths in a row using one's own timing without having to push up the pressure on the machine. Anyone who has normal upper airway musculature can frog breathe. Occasionally someone with polio has had soft palate weakness, and the air will leak out the nose, and people will use a nose clip, especially at night. I would estimate ten per cent of the people who use mouth positive pressure need a nose clip.

Adolf Ratzka leaks out of his nose when he uses mouth positive pressure, so he developed a face mask which covers his nose. One of the people that he was talking to last year went home to her dentist and developed a face mask which allows one to breathe through the mouth with a bite plate and seal. It's all made of acrylic, and she has the airway through the nose as well. One is breathing through the nose and the mouth simultaneously, and the whole thing can be used without any face straps. People have asked, "What if you vomit or choke and you've got it strapped around your head?" In the 25 years we've been using it, it's never presented a problem, but theoretically it could. When one uses it without any straps, the whole thing would probably be projected out of the mouth at that point.

When one uses mouth positive pressure during the day, there may be a little extra saliva, but it's very quickly accommodated. Saliva is a problem in the far-advanced muscular dystrophy who has severe throat weakness already. Many of them will come in with a lot of saliva in their throats, but if one gets them strong again by continuous assisted ventilation, the saliva will disappear, so that one doesn't have to go to a trach.

When do you change to a trach? You change to a trach if the oropharynx was too weak to hold a positive pressure apparatus, if you were in a very obtunded state, in an ICU, or very toxic.

Some patients who need a trach at night prefer not to button it during the day and to stay on a trach during the day. It's their choice if they wish to keep this open, even though I feel more drying, more turbulence, more chances of infection will occur if it is kept open. Many of the spinal cord injuries keep their trachs. They'll either go to free time on no respirator with trach buttoned and open it at night to use the ventilator, or they'll stay with it open all day long.

We found that our small children have ended up in the acute hospitals having been tracheostomized, and I remember from the days before we did trachs on small kids, they just didn't survive. I know of only one that survived into adulthood with polio at age four without a tracheostomy. Small children are better off with a tracheostomy than mouth positive pressure.

With a trach, the question is whether one needs a



cuff. One person said all of his trach tubes were without cuffs. There are people who are so weak in the throat, especially in sleep, who need a cuff on the tube. Some of them need that cuff partially inflated during the night, and there's a very rare person who needs it fully inflated during the night.

What is a zephyr? It's nothing more than the pressure on the other end of a vacuum cleaner, only it's sound-proof. It's a steady stream with no cycle. It's a wonderful machine if one only needs to sigh the lungs and to help cough. If one wants to take a deep breath in order to cough, or to sigh, use a cheap little zephyr.

The Thompson Bantam has a high and a low switch, but after the Thompson GS and the LIFECARE RBL, all of the other machines that are being designed today, except for the MaxiVent, are volume ventilators. The advantage of a volume ventilator is that it draws less current so it can be used 24 hours on battery, a distinct advantage for anyone who's outside of the home and doesn't want to worry about the battery dying in midstream. Bantams draw much more current.

The M-25 is about all many people need at home for a positive pressure ventilator that will be used for a long time on battery, and it is a volume ventilator.

If a respiratory therapist brings an M-25, the majority will be able to breathe on it perfectly well without going to a sophisticated M-3000-XA. The MaxiVent doesn't have a battery and it lasts much longer. One of our patients has used it every night for three years at the bedside with not one problem. The motor doesn't have brushes in it the way those with a battery do, so that is one of the advantages of the MaxiVent. The other advantage is that one can use it at bedside for mouth positive pressure or trach positive pressure.

Life Products has the LP-3, LP-4 and now the LP-5. The LP-4 has definite advantages over the LP-3. LIFECARE is still renting the PVV, as they call the LP-3. A variable i/e ratio (the amount of time for inspiration in the respiratory cycle compared to the time for expiration) is important for some patients, especially during the night.

The weight of the machines, the height and the depth are important if they are placed on the back of the wheelchair. If one requires a large amount of oxygen, it's important to know how one can get oxygen through the machine.

LIFECARE's PLV-100, has digital readouts, and they vary from moment to moment. The inspiratory flow is shown, as well as the i/e ratio, tidal volume, and frequency. Someone with no free time on a tracheostomy, especially a small child, might prefer a PLV-100.

I have no experience with the BEAR 33. Bear has been manufacturing ICU equipment, especially for children, and now they've come out with a portable home ventilator for adults and children.

What kinds of problems occur with the teeth holding on to the positive pressure hose for 5, 10, 15, 20 years? The angulated white hose is very hard, which some of our patients have loved because it falls right into the mouth. One of the ladies who uses that hose had a great deal of loosening of the upper incisors, so they had to be reinforced in the back. The lower incisors became so loose that they had to be extracted, and she had what is known as a Maryland bridge put in, which is a permanent bridge attached to the two canines. The throwaway mouthpieces that go with the nebulizer equipment or with the lipguard are much softer, but they're not soft enough that one can completely obstruct them. They're kind of springy with rubber on the outside onto which one's teeth can grasp.

If one uses the Thompson gray mouthpiece in the corner of the mouth all the time, the lower molars can become tipped inward. If a mouthpiece in general is used all the time, the bite may be moderately open in the front as a result of using it. But I think these are small prices to pay compared to the disadvantages of a tracheostomy.

They're making a transparent mouthpiece, but it still is hard. Even the gray one wasn't that soft. It was a hard tube. Everybody liked it, but I don't know how good it was for their teeth.

If we did put a little piece of rubber on the outside of a mouthpiece, this would be good for the teeth, rather than having the hardness, just as we have the rubber on the lipguard mouthpiece. One could take rubber hose from the laboratory and slip it right over the regular mouthpiece. We don't think of these things because we're not concerned about the teeth initially, until we see what happens 10-15 years later.

Drying and heat are going to create more periodontal disease. People who are quadriplegic depend on their attendants to provide dental hygiene. The combination of peroxide and baking soda which has been popularized for periodontal disease is a good idea. I don't think one has to do it every night, two or three times a week is enough.

Goose necks, which are semi-rigid and come from a hardware store, come in pieces that are 12 or 18 inches long, and used with two hose clamps, will stay rigid on the post of the wheelchair, the posterior post or one of the handles. One puts the mouthpiece back there and swings it around like a microphone, and it sits right up in front of the mouth. People reach for it when they want it, and they let it sit there when they don't want it.



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## Workshop on Sleeping With a Face Mask

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by Adolf Ratzka, Ph.D.

The face mask allows me to breathe through both mouth and nose. If I have my mouth closed during sleep which I usually do automatically, I get all the air through the nose. When I have a cold and my nose is plugged up, I use nose drops and an on-line Bennett Cascade humidifier.

One of the drawbacks of my mask is the fact that the seal is not perfect. In order to compensate for leaks, I have my LP-3 deliver 3 liters with each piston stroke. Three liters at a rate of 15 per minute for a period of eight hours makes the motor work harder than it was designed for. As a consequence, I have to have it frequently serviced. A solution would be to decrease the area of contact between mask and face, thereby decreasing the possibility of leaks.

At the conference in 1983, I demonstrated my extended mouthpiece of dental acrylic that was fitted on my teeth and has an opening between the teeth. The air comes through both teeth and mouth. Bruni Bung from Munich has continued along the same lines. With her mouthpiece she can choose whether the air is to come through mouth or nose by connecting a small hose from the ventilator to either nose or mouth opening. She can do the switching herself, since she has good use of her hands.

A further improvement would be to design a valve that could be operated by the tongue and would allow the user to select a flow consisting of air through mouth only or through nose only or any combination in between.

One of the problems using mouth positive pressure is the drying of the mouth. If you hold a regular pipe-shaped mouthpiece between your teeth and try to sleep this way, the mouth will soon dry out. That can be quite painful and you'll wake up. Some people, I understand wake up frequently during the course of the night and sip ice water. Other users develop a hard mouth, as it is called, who claim that the tissue inside the mouth with time undergoes some changes and will take on the function of irrigating itself. Active humidification has its problems too. The hose from the humidifier up to the face should be as short as possible and vertically straight to avoid condensation. If room temperature is too low, condensation will reduce the humidity of the air which reaches you. If you try to compensate this by turning up the heat of the humidifier, it can happen that air humidity turns into sizeable water drops which squirt into your mouth and you hear gargling sounds in the hose all night.

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## Sex, Disability, And Aging

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by William Masters, M.D.

We use the term "sex" to mean physical activity — masturbation, intercourse, oral sex — and "sexuality" to connote a dimension of personality of our masculinity or our femininity. These are not synonymous words in our lexicon.

Sex is a natural function, and yet, not one man or woman in this country has ever been privileged to live with sex as a natural function. Our culture has denied us that privilege.

The first time I ever encountered sex as a natural function was my first delivery as a brand shiny new intern. I watched open-mouthed and open-eyed as the baby emerged, and was immediately attracted to the fact that not only was it a boy, but that he had an erection, and he had this erection before he took his first gasp. I had had no concept that such a thing would occur.

We now have some beautiful pictures of baby boys in utero, a month or six weeks before they're due to be delivered, with full erections. We know, although we haven't published yet, that baby girls involuntarily lubricate in the first 8 to 12 hours of life. Erection in the male and lubrication in the female are parallel phenomena created by the same blood supplies, the same types of tissue, and the same nerve supply.

What about sexual activity? Presuming there's no organic influence, every man, regardless of age, has an erection every 80 to 90 minutes all night long, in or out of dream sequence. Presuming there's no organic dysfunction, every woman involuntarily lubricates, regardless of age, every 80 to 90 minutes all night long, in or out of dream sequence. How does that apply to this audience?

Some of you have difficulty dealing with natural functions, and so you have difficulty dealing with sexual functioning, but not because sex is any different from anything else. Many times these distresses can be reoriented, reversed, revisited with adequate direction and support.

There is much misconception of sexual functioning, particularly among disabled individuals. The first step is partner consideration. Inevitably, partners do the wrong things for the very best of reasons. It is important that the couple be educated in terms of how best to approach their particular distress.

How is sex affected by the aging process? If sex is a natural function, then it must go through changes as we age. These changes start in the late 40s or early 50s.

For the male, it takes longer to achieve an erection in his 50s, 60s, 70s, than it did in his teens, 20s and 30s. What difference does that make? Absolutely none, as long as he and his partner know that.

There is some reduction in ejaculatory volume, in ejaculatory pressure, and, above all else, there's some reduction in ejaculatory demand. That applies at any age group when there's some disability. When I say reduction in ejaculatory demand, I mean that he may not want to ejaculate every time he has an erection or even with the penis in the vagina.

The man should ejaculate at his own demand level. I can only think of one time, one set of circumstances in which he must ejaculate on demand, and that's if the couple is trying to become pregnant. The same thing applies in the handicapped individual. Can a male have an erection and thoroughly enjoy exposure, manipulation, penetration, if possible, without ejaculating? Of course.

Sexual interaction in a committed couple should not be entirely male-oriented, despite the fact that he may have the disability, and it shouldn't be male-oriented if he doesn't have the disability, because sex for the female is a natural function also. There's a great deal of research done on sexual function of the handicapped male; incredibly less on sexual functioning of the handicapped female.

What happens to the female as she ages? If lubrication is the exact parallel of erection, then there should be some

reduction in the amount of lubrication produced, and that's exactly what happens. There is some loss of expansive quantity of the vagina.

Presuming a reasonable state of good general health, and unless the handicap is organic in origin, in order to function effectively regardless of handicap or regardless of age, one only needs an interest in an interesting partner, and I'm referring to the 80-year age group. The concept that as a male or female ages they lose capacity or interest in sexual functioning is utter hogwash.

What about sexual functioning in the handicapped? We first make the diagnosis of organic or psychogenic origin. If the basic affliction is organic, it does not mean the impotence is. It may well be, but it is not complete parallel orientation, and this should be evaluated as quickly and rapidly as possible. Because one has psychogenic impotence or because one has lack of knowledge of what to do and how to do it, it should not handicap one from an effective sexual interchange. In a committed relationship, effective sexual functioning is one of the better, if not the best means of nonverbal communication that we know. We define communication in a committed relationship as the privilege of exchanging vulnerability.

A tremendous bond frequently is abdicated, sorely missed, voided, moved away from, primarily because those in authority from a health care point of view do not know how to introduce the subject, or what to do if the subject were ever introduced by the patient.

We are available to any handicapped individual by telephone (314/361-2377) or, of course, visitation. We will discuss very briefly the problem and present the concerns as we see it. If it is a simple thing as sex education, and at least 25 to 30% of the time it is, it's our privilege to help. If other types of help are needed, we're also available.

We work in a rapid manner at the Institute. All sexual dysfunctions, disorders, and dissatisfactions are treated in a two-week interval, as opposed to the prior two or three-year concept. If one has difficulties of major moment, one has a significant chance of reversing these in a couple of weeks' time. These individuals, of course, are followed actively for a long period of time thereafter.

## Questions & Answers

**QUESTION:** *What about people who don't have money and need the highly qualified sexual therapists that you were referring to?*

**DR. MASTERS:** The Institute charges on a sliding scale, and roughly a third of what we do is either for just a fee or free care.

**QUESTION:** *Could you comment on sexuality in institutions or long-term care facilities?*

**DR. MASTERS:** We had the privilege of meeting here in St. Louis in 1970 with the nursing home owners and operators. We suggested to them that there be a recreation room established for inmates, and they said, "We'll do it, but it'll

cost us money." I said, "Oh come on, it doesn't cost you much to fix up a room with a bed, etc. etc." They said, "Oh, no, we don't mean that. We're going to lose patients." Those that established recreation rooms did lose some patients. Their sons and daughters who were supporting them there took them out. They didn't dare have their friends think, "Look what your mother is doing." These were the same men and women who had sons and daughters in college in open dormitories, but that was different. No concept of sex as a natural function or of sex in the aging process.

Should there be such an opportunity in institutions? Of course. We continue to talk about it and everybody continues to say yes, and walks away from it, because most of those institutions have public fund support, and there'll always be somebody who says, "I don't want my money spent on sex." Medicine has moved only so far. The first required sex course ever taught in American medicine was taught in the 1960-1961 academic year. Any man or woman who graduated before 1960 hasn't had a minute's training in human sexuality, unless they had it in post-graduate training. As of the 1983-1984 academic year, three medical schools still refused to allow the subject to be taught to medical students.

Medicine's painted itself into an incredible corner. It's perfectly all right now to treat dysfunctions, disorders, and distresses. It's all right to use surgery for penile implants.

However, when a routine history is done, questions are asked about the cardiorespiratory system, the GI system, the GU system, but no questions may be asked about the sexual functioning system. Less than 20% of the hospitals allow such material in the records. It's all right to treat the distress, but you can't ask the patient if he/she has it.

### **QUESTION:** *What about the cultural misconceptions about male and female sexuality?*

**DR. MASTERS:** The culture has always been quoted as being restrictive and repressive of the female — the "thou shalt nots." Yet, the culture is infinitely more repressive of the male than it is of the female, because he has to compete with "thou shoulds."

The male is supposed to be the sex expert. It's a role that most men are moderately forced to accept. He's supposed to be responsible for the female. How? Aid and abet, certainly. She can aid and abet him, but he can't be orgasmic for her any more than she can ejaculate for him, but the culture doesn't say that.

Finally, the thing that destroys the male ego is that he's supposed to be the one with the greater need and the greater capacity. Yet, the female has an infinitely greater capacity to respond to effective sexual stimulation than the male ever dreamed of having.

## **Reactions to Dr. Masters**

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### **Judy Heumann**

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Last week, Ed Roberts, Adolf Ratzka, and I lectured to a group of nondisabled persons who were studying special education. We assumed that the talk was going to be about educational issues, and we each talked for about 20 to 30 minutes about our own experiences. I'm a former public school teacher who still lectures at the university level, and I talked about my experience as an educator.

Then the prof told the students that they should write down any questions. The questions were very widespread, and there were a significant number of questions dealing with sexuality. It became obvious that it was very important for those individuals to ask basic questions like, "Do disabled people make love?" and if so, "How?"

What I realized through that discussion was the importance of giving people permission, both nondisabled and disabled individuals, to ask questions about other people's sexuality.

Even people with different disabilities do not fully understand what sexuality is all about with other people. Although disabled by polio, we have full sensation. The first time I had a relationship with a spinal cord injured person, I recognized how I had been isolated from my body. He only had sensation from the nipples up.

I talk to women all the time, disabled or not, about how we've missed out on not recognizing that our entire body is very important. Sexuality is much more than sex. It's the way we dress, it's the way we smell, it's the way we interact with people, it's the way we teach disabled children how to be able to be sexual.

I think there is a large number of people in this society who are not in coupled relationships. Many of us might very well want to be in a coupled relationship, but don't want to be unable to be sexual or have a meaningful sex relationship until they find a committed partner.

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## Kathy Jagoe

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As disabled people, we are aware that in the whole continuum of discrimination, perhaps discrimination in the area of sexuality or intimacy is the hardest to break through. Being accepted as a sexual person in an intimate relationship is the last area of discrimination to crack.

It's the responsibility of disabled people to educate people. When one is asked questions like "Do disabled people make love? How do they do it?", we don't necessarily have to talk about our individual relationships to answer. We can talk more broadly about ourselves as human beings. As disabled people, we are no more or no less sexual than if we weren't disabled, or than the rest of the general population.

It's our responsibility to educate other people, not only through information, but through the kinds of people we are, the kind of openness we express to other people, the intimacy we are able to risk (and I do think intimacy is a risk to allow ourselves to be vulnerable). I think that to expect able bodied people or any other people to see us as being sexual is only possible when we ourselves see our own bodies and our own selves as being sexual and desirable. We must like ourselves before we expect anybody else to like us.

It took me a long time to move from adolescence to adulthood where I had all kinds of stereotypes dumped on me. The medical profession, my friends and family, and society in general saw me as an asexual person. It took me a while to see that, in fact, I actually did like myself, and I did like my body, and that by liking myself and liking my body, perhaps I was teaching other people around me to do the same.

Literature on sexuality and disability is available. The one piece of literature that made an incredible impact on me is Elle Friedman Becker's book, *Female Sexuality Following Spinal Cord Injury*. Some people are more advanced in their awareness of their own bodies and certainly the people that Becker interviewed in her book were people who liked their own bodies. Another book is Yvonne Duffy's book, . . . *all things are possible*.

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## Jack Quigley, D. Min.

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I am a pastoral counselor in addition to being a disabled person, so I have two areas of life experience to draw on: my clinical and my own personal experience.

I spend a great deal of time helping individuals who are both able bodied and disabled unlearn the things many of us have been taught about our own sexuality from the time we were born. I agree wholeheartedly with Dr. Masters, that our sexual functioning and our sexuality as a whole is very much a natural function of our bodies.

Those of us who are disabled have been afforded an opportunity to be more aware of our own bodies, more aware of our own needs, more aware of our own vulnerability, than the population at large. Thus, we have an even greater opportunity to discover ourselves and to express ourselves in ways that many people never can. We have a mission to those who are able bodied people, who perhaps

are in one way enjoying their sexual lives more comfortably, easily, and fully than we, to show just how open people can be about their own body functions. We are not always the ones in need — we have something to teach.

I am psychoanalytically trained and I began studying Freud early in my training. Sexuality really is — as Freud said — the source of energy in all of our lives, and, if that energy is repressed, we are less than fully equipped to deal with all the other aspects of living that we are all required to deal with. If those of us who are disabled are in any way cut off from our own sexual energy sources, we are cut off in some way from the very source of energy that helps us to live comfortably with ourselves.

Rather than being an afterthought in rehabilitation, physical and occupational therapy, etc., sexual education, sexual experience, frank discussion of our whole selves both physically and emotionally, is of the essence in rehabilitation. Sexual education and experience is then also of the greatest importance throughout the rest of our lives as a way of liberating that source of energy that can help us live freely and comfortably.

Dr. Masters talks about the importance of education, and I wish there had been someone to educate me about my sexuality in the context of my disability. There is an infinite variety of physical-emotional responses that we as human beings are capable of, but of which we know very little. The highly specific genital sexuality that is usually referred to when people talk about sexuality is but a piece of a broad spectrum of responses. When people talk about orgasm, they usually are speaking about something that is a totally genitally stimulated phenomenon. To limit sexuality to genitally stimulated orgasm is simply incorrect and inadequate.

Our physiological and emotional responses can be stimulated in a variety of ways, and there can be a completely orgasmic response to various forms of stimulation that have little to do with genital sexuality. Many of us who are disabled tend to limit ourselves in enhancing genital sexuality. It would be far more natural and easier for us to engage in modes of sexual expression from other parts of the spectrum, rather than limiting ourselves by focusing only on genital sex.

I would like to reinforce Dr. Masters' comment that sexuality is the privilege of exchanging vulnerability. We, above almost anyone else, know something about vulnerability. Part of what I encounter clinically as the source of sexual dysfunction among able bodied people has to do with an inability to touch one's own vulnerability: in men, a macho sense of the assertion of power and domination; and in women, an uncritical acceptance that those modes are the proper modes to which to respond.

My sense of us is that if and when we are able to dwell in our own vulnerability and expose ourselves to another person as we really are, the richness of our own sexual experience will be much greater in fact, than the sexual experience of those who feel a certain pressure to perform. When it is difficult at times to generate self-appreciation completely from within, one of the things that helps us to understand and appreciate our own bodies is to be engaged in sexual interaction with another person. The kind of appreciation that we feel coming toward us from another person is the very best source of help in under-

standing that we are whole and stimulating persons. We offer back the same to our partners. It is extremely difficult for any of us always to find within ourselves the feelings of self-affirmation we need to be happy. How much more fulfilling it is to engage in relationships where that mutually affirming exchange can take place. It can set us on the road to self-affirmation in a way that we might not be able to find for ourselves.

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### **Irving Zola, Ph.D.**

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It is clear we owe a great debt to the work of Masters and Johnson. They have clarified in many ways that sex is a natural function. Dr. Masters spoke about sexuality as culturally bound, and to a certain extent, historically bound. For a full understanding of these issues, we must turn to the writings of the women's movement over the last decade.

*Our Bodies Ourselves*, and the latest edition, called *The New Bodies Ourselves*, has considerable material on aging, as well as material written by women with disability. As they note, the extraordinary emphasis on sexual performance is one of the greatest curses for men and women alike. It is phrased in the ability to achieve an orgasm, an erection, an ejaculation, etc. Yet sexuality involves many parts of the body and many phases of life.

Sexuality is something which we can experience by ourselves. We can also experience it with members of the other sex or with members of our own sex. To restrict our discussion, and even our understanding of sexuality to one mode, one act, one gender, can only contribute to the oppression that we as disabled people experience.

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### **W. H. Verduyn, M.D.**

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I went to a Sexual Attitude Reassessment Seminar about 1975 and rediscovered myself as a human being and a sexual being. There is a group of physicians who are actively involved in counseling and working with disabled people. Many of these came out of the spinal cord injury model. Theodore Cole and Sandra Cole are well known, and anyone who needs information can write or call Sandra Cole at the University of Michigan in Ann Arbor.

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### **Harlan Hahn, Ph.D.**

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I am trying to establish a program in disability and society at the university where I teach. In surveying the literature on sexuality, as well as the whole range of other issues, I discovered that our own experience as disabled people tends to get omitted from the information we have available about this subject. I have begun planning, with a clinical psychologist in Los Angeles, Dr. Carol Gill, who is also disabled, a survey on the experience of disabled people with sexuality. We are attempting to develop a broad sample of people with disabilities from a variety of disability

categories. This is an effort to gather vitally needed knowledge and information about this subject. All of the information will be confidential. Your names will never be attached to anything. It is extremely important information that needs to be compiled and that needs to be communicated to other people with disabilities.

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### **Saul Boyarsky, M.D., J.D.**

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Most of the people here are more experienced in their sexuality than we physicians are. You know more about your own sexuality, you know more about the problems you have encountered.

Good doctors try to learn from one patient what better to tell the next patient. I reach out to you as professionals as well as disabled with this observation to encourage the dialogue you have developed.

Doctors are in a predicament, trained before any sexual physiology was written by Masters and Johnson. Today's doctor may have been trained in the era of Kinsey; he may have been trained in the era of Freud on sexuality. Each is a relic, one a Model T and the other a venerable horse and buggy. Most doctors know this and are a little uncomfortable with sexual questions in their office.

John Money, the famous psychologist and sexologist, put it best at a seminar we had several years ago where we were trying to exhort more research on the male side when he said, "After all, look at doctors and medical students. They're overstressed, overachieving, undersexed, workaholics." Their understanding may be limited without more knowledge, training, and experience. And their sexual values certainly must not be imposed on their patients. The patient's values must be respected and usually should govern.

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### **Jack Genskow, Ph.D.**

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If you've had polio, sex is important; if you haven't had polio, sex is important. But when you've lost a lot of what you can do, those things that remain become more important. For those of us who have had polio, sex still works. It's a great source of pleasure, and has heightened importance in some of our lives.

Dr. Masters discussed the concept of sexuality versus sex. That tied in with a Sexual Attitude Reassessment Seminar my wife and I attended at the University of Minnesota in 1975. It was pointed out that only  $\frac{1}{3}$  of the word "sexuality" is sex, relating to genitals. The "uality" is the much broader part of the word — the other  $\frac{2}{3}$  — the relationship with others, the intimacy, the more subtle pleasure.

That seminar was for people with disabilities and those who work with people with disabilities. At that time, very few people dealt with sexual issues of disabled people. None of the professions did. The physicians didn't, the nurses didn't, the PTs didn't — nobody dealt with sexuality. Almost no one in the medical community, or who worked with people with disabilities, was ready to deal with the sexual aspects. That's better now, but it's still a

problem and a concern for those working as peer counselors, or those who are currently working in the medical community. To help people with their sexuality, you must get in touch with your own first.

Perhaps one role of sexuality in aging, besides playing

a role in pleasure and intimacy, is one of a continuing thread of experience in our lives which helps remind us of that youthful, energetic person still within us. In our fantasies, it helps remind us of who we were and in reality of who we've become.

# Meeting the Challenge of Aging

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## Mickie McGraw, A.T.R.

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Two years ago, at the 1983 Conference I spoke about positive attitudes and wellness — about the relationship between our attitudes and our ability to deal with post-polio aging problems. I'm two years older, and consequently, I've changed both physically and emotionally. In most respects, however, my changes were unrelated to, or unaffected by my post-polio condition. In fact, even though two years are gone, many of the changes have been positive and have been lasting.

I traveled, I got a raise, and I was even able to do some more of my own art work. I also have a few more gray hairs, I find it a little harder to lose weight, and I must admit, I had a very sinking feeling when I realized I was going to be 44 this year.

My attitudes have also aged. There's been a monumental turn-around in my thinking or my approach to life — just a growing awareness that the issues of aging and wellness are universal, and I think should be thought about in that context. The ability to meet the challenges of aging begins and ends with each one of us.

Certain attributes and abilities must be developed to insure a quality of life and a quality of aging. They include the ability to adapt and to maintain a personal balance and control. These are qualities that are necessary to all people. Our ability to adapt, to change and to grow, in response to life's situations, is critical to our well-being.

Our own past experiences are proof that there are ways around and through whatever may seem insurmountable in the present or the future.

Balance is also essential. Learning when, how, and for what energy should be expended requires self-knowledge and self-control. Maintaining our physical and psychic balance prevents pushing beyond what is healthy, and most importantly, it preserves our ability to maintain control of our lives.

As a disabled person, I had to learn how to take and maintain control of my life, even though I had lost control

of much of my body. I had to set the example by my own attitude. How I feel about myself, how I feel about my body, and how I feel about my inner self makes a person relate to me in a particular way. By that example, and by being comfortable with my disability, others follow suit. This, however, is a process that is ongoing; that is both intuitive and learned. It's something that doesn't stop.

Much of the focus of this conference has necessarily been on the problems specific to our disabilities, particularly on a functional level. However, I am struck with the nonspecific universal nature of our concerns. Many of our concerns as post-polio and/or severely disabled individuals are common to all people. Anxiety related to loss of control, fear of the unknown, and pain from emotional and physical loss, are part of our human condition, and are particularly prevalent as we grow older and become more physically limited or restricted. A major difference between us and them, between disabled and nondisabled individuals, is that we have experienced significant physical losses and limits prior to those normally experienced with aging. Along with this difference comes a positive side and a negative side.

On the positive side, we have already faced these situations. We have experience with handling them and with dealing with the ramifications. We know ourselves with limits. On the other hand, our disability may make the aging process more difficult, and dealing with loss or limits the second time around isn't always easier, contrary to what people might say.

Many of the coping mechanisms that we have developed in order to get on with our lives are not compatible with adjusting to further restrictions. The DIBTYNP syndrome is the "Do-It-Better-Than-Your-Nondisabled-Peer" syndrome. Those things that we've developed to compensate, both realistically and unrealistically, get in the way of listening to the advice, "Let's take it easy." When I get tired and I've had a very busy day, my tendency is to believe "Well, it's because I'm in a wheelchair." My colleague goes home and takes a nap. I don't, because I've got to keep on

going. We have to pay attention to these things ourselves; no one can change these attitudes but us.

We must get back to the lessons that we learned the first time around and make them work for us again. The pains, the weakness, the fears, the concerns are very real, but they can be dealt with, and they are not ours alone. We must challenge the stereotypes about the process of aging and challenge the negative stereotype attached to that phenomenon.

Our Western culture instills negative attitudes in all of us by the way we honor, validate, and promote the young, while we avoid, isolate, and even deny the elderly. All of us are at some point along that journey right now, and each point has its own joys and its own pains. What was necessary and pleasurable to me yesterday may hold no interest for me today, while some of my earlier enthusiasms will move with me through life.

As I change externally, due to age, illness, or a new hair style, so, too, do I change inside. We all go through this process very differently. We struggle with some parts, and we flow with others. I think it is important to be reminded that, what at first may be or feel like a limit, can become a freedom or an opportunity for growth.

It is important to remember that we don't have to buy into someone else's stereotypes about aging, about disability, about sex, or all three together. If 30 years ago we had bought into the stereotype about "the handicapped," we wouldn't be here today.

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## Naomi Harward

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I am a national chairman of the committee of the Gray Panthers that is working on developing a better relationship with disabled individuals.

The challenge of aging is what we make it. As I watch those of you getting around here, I urge you to continue to be challenged.

It's different somehow for some of us in my group. I taught social work at Arizona State University for 20 years. It is a great thrill when you retire from a job and you realize you no longer have anyone who can tell you what you have to think and do. A new freedom arrives with old age. It can be a very positive thing.

We senior citizens have learned to take advantage of every opportunity to present our needs and make people more aware of the importance of recognizing us as individuals, not stereotypes.

The Gray Panthers' motto is "Age and Youth in Action." We believe very much that the elderly, the disabled, and the youth are outside the mainstream of our society. Society decides what we should have and how we should act. We must coalesce and work together to help society understand what we need and what we should be doing. We must be concerned that our society does not overlook the needs of individuals of any age or any situation.

We do not have much use for these life care centers where we are encouraged to go to live our final years. As we get older, most of us have two or three chronic conditions that require continuing medical care. We have Medi-

care, but I don't think that I have to tell you that Medicare only pays about 44% of the bill.

The insurance companies won't bother with small businesses, or the elderly, the homeless, many minorities, the youth. They only want the large companies. We believe in national health service. We do not want national health insurance, we want a national health service. We must have a medical system that takes care of all people, all ages, and all situations.

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## Jill Tarbel

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I belong to the American Association of Retired Persons (AARP). My husband, Brook, and I wanted to participate in their national meeting. I called to ask if the meeting was accessible. "What do you mean by accessibility?" I said, "Well, we both use wheelchairs. Is your meeting going to be accessible to people in wheelchairs?" "We'll have to call you back."

They called back the next day and said, "Well, yes, but . . ." and went into a long explanation of how you get into the auditorium, etc. I then asked, "By the way, will you have large-print agenda? Will you have signers for the deaf?" Again a big pause. I said, "You're not meeting the needs of a lot of your membership, are you?"

This led to many more phone calls, and finally AARP invited me to Washington last August. AARP now has said they are going to hire a person to talk and deal with the issues of the aging disabled. I pointed out that they never show a person with a disability in any of their literature. Everybody past 55 in the magazine is out playing golf, taking cruises, etc. Older people who become disabled go through the rehabilitation process, go home. If they pick up the AARP magazine, they won't live up to AARP's stereotype of an aging person.

Phyllis Rubenfeld, president of the American Coalition of Citizens with Disability (ACCD), has written a paper to be published soon on "Aging and Disability, Double Jeopardy." We must work together or we will have the Gray Panthers and the Disabled Gray Panthers.

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## Jack Genskow, Ph.D.

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Remember those of you who had polio, what it was like in those early days. For me, it was walking one day and in the iron lung the next day. I could wiggle my left fingers and my right toes, and a little bit of my right arm. I could turn my head one way, but I couldn't turn it back. And I couldn't breathe. I felt a lot of anxiety, a lot of concern, a lot of fear. But there was some hope, too, in that there was always the return of muscle usage. Up to two years, some people kept getting partial return. We had anxieties about those muscles as they returned, but we used denial against our anxieties. We defended, we displaced, we repressed. We never really dealt with those anxieties.

Then we went into a long plateau phase. A gradually descending plateau, as it turned out, which we didn't realize was going that way. Now it's 30 years later. We're begin-

ning to notice loss, and where do we notice it most? In those muscles that began to return in those first six months — the ones in which we have the most anxiety invested. Therefore, I think the experience of loss of function by a person who had polio is different from the loss experienced by a person who is able bodied because it taps into early anxieties. These anxieties were probably never dealt with. The return of functional usage earlier resolved the problem, but this time, as we experience loss, that usage won't return. The anxiety we're now experiencing is a qualitatively different response from that experienced by other people simply because it relates directly to that earlier polio experience. We have to deal realistically with the loss that we're experiencing. It doesn't help to pretend it's not there.

If you have fears or anxieties which are getting stronger, see a counselor, a therapist, or a friend, because you may be dealing with issues that you've never fully dealt with before about your disability.

How we think about our disabilities is extremely important. We must be careful about the words we use, because words are very subtle influencers. I've been labeled a disabled person, but I don't feel like a disabled person. I feel like a person who happens to have a disability. I'm a person first, and that's what's important. Someone said, "You're confined to a wheelchair." You're not confined to a wheelchair. The wheelchair's an enabler. It frees you. It gets you out of bed, gives you mobility. If you think in terms of being confined to a wheelchair, you draw into yourself. When you feel enabled by a wheelchair, you're free.

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## Ronald Doneff, M.D.

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We must continue to live as we have lived, to cope as we have coped, or find new methods of coping if we have to, and to enjoy life. Nothing is going to get any better as we get older. We're going to deteriorate the way all of our able bodied peers deteriorate. We have to face that.

I would encourage all of you to learn to use all of the available assistance, all of the types of respiration, all of the types of mechanical aids and crutches and chairs, because they will serve you at different times and different places in different ways.

I know that there are logical answers for a lot of things that may be too quickly attributed to post-polio problems. It took me four years to realize that all of my problems are due to my scoliosis. I kept getting a weaker right arm; I kept being unable to raise my head; I kept being short of breath. That's all due to my scoliosis. I've lost the fulcrum for my elbows. Older people as they walk are a little bent forward with a very straight low back. The natural lumbar lordosis has been lost, that little curve at the small of the back. That's why I can no longer raise my head.

Aging is often a regression to the lowest level of achievement. Muscle strength can be built up, but people will slip back to what they're used to doing. We have to avoid complacency and comfort. We get very comfortable with the way we've always done things, and we're very reticent to change.



# Conquest of Polio: Unfinished Business

by Albert Sabin, M.D.

If people were asked, "Has polio been conquered?" many in the United States and in the world would answer, "Why, of course." It's true and it's untrue.

It is true that in the past 20 years in the temperate climate countries with fairly adequate health services, an estimated 5,000,000 cases of paralytic polio have been prevented in countries with about 2,000 million people using oral poliovirus vaccine. It is also true that in the poverty-stricken, undeveloped countries of the tropics and subtropics inhabited by more than half of the world's population, there is more paralytic polio now than we had in the United States or in the temperate climate countries in Europe before the introduction of vaccine.

This was discovered, not on the basis of reporting, but by lameness surveys looking for children and older persons with paralysis that could only have been caused by polio. On that basis, there has been an extraordinary variation in what the annual cost in paralysis is in Africa, Asia, and Latin America. The figures for the United States are so mixed up that they're absolutely worthless without some sort of a breakdown, because there were all sorts of things included that were not polio — non-paralytic polio, and polio that quickly disappeared within weeks or months that were mostly caused by other viruses. The best estimate I've been able to arrive at is that in the pre-vaccine era, on the average (and polio occurs all the time, whether there's an epidemic or not), there were 135 paralytic cases per million total population in the United States. Since the mass immunization with oral polio vaccine that started about 22 years ago, it has been reduced to about four per hundred million, and in 1984, there were only four cases reported per 240,000,000 people for the United States.

Paralytic poliomyelitis — typical, classical poliomyelitis — is caused not only by the three types of poliovirus, but also by other so-called enteroviruses that are parts of the same biological family. It will never be possible completely to eliminate paralytic polio down to the last case, the way it's been done for smallpox, because the vaccines against the three types of poliovirus cannot be expected to eliminate the disease caused by the other viruses. Nevertheless, a change from 135 per million, which would be 13,500 per hundred million to 4 per hundred million represents a conquest.

Why is it that there's still so much polio? The World Health Organization estimates an average for one year of 400,000 cases of paralytic polio in 1983. We can expect that in 10 years, there will be 4,000,000 more, because those who develop paralytic polio and don't die, live — if nothing more is done.

What can be done? It must first of all be realized that in the tropical and subtropical countries with poor sanitation and hygiene, polioviruses circulate much more exten-

sively in the population. (Many people don't know that polioviruses are transmitted through fecal contamination, and that the viruses multiply in the intestinal tract.) They circulate year-round, and 10 to 100 times more frequently than in temperate climate countries, so that procedures of mass immunization followed by routine vaccination, which proved effective in the temperate climate countries, are not effective. Furthermore, routine vaccination reaches only a small proportion of the population of the children. There are more than 100,000,000 children born a year in economically undeveloped countries. It's estimated that 70,000,000 or more aren't vaccinated at all.

The problem up until now, and still remaining in most of the world, is that the procedure of vaccination has been modeled after that in economically developed countries. Bring the children, whenever they can be brought, to a maternal health center. Give them vaccine year-round and you reach a small proportion, and polio goes on. It was first shown in Cuba 22 years ago that if you give oral poliovirus vaccine at once, twice a year, bringing the vaccine to the homes of the children under four or under three years of age, polio can be eliminated within one year. By repeating this program each year without counting numbers of doses of vaccine for all children under three or four years of age, control has been maintained.

Brazil decided to do a similar program in 1980. Because Brazil is a huge continent with 125,000,000 people and almost 18 to 20,000,000 children under 5 years of age, Brazil organized an army of about 320,000 volunteers at 90,000 vaccination posts that were within walking distance. The first dose of polio vaccine was given in June, and the next one in August. Within that year, poliomyelitis dipped in a manner that never occurred before. They've done the same program every year now for five years. It has to be done every year. Each year, you have a whole new cohort of children with susceptible intestinal tracts in whom intestinal resistance to infection must be developed.

In 1983, the Dominican Republic organized a program along the Cuban style, which means to take the vaccine to the homes. This does not make poor mothers walk miles to drag children to some post where they may or may not arrive in time. It brings the vaccine to the homes. The Dominican Republic, which is an undeveloped country, showed that they could get organized by choosing the proper people. Then Bolivia did it.

In 1984, the United Nations Children's Fund organized a special campaign in Colombia. Colombia, with a population of about 29,000,000 persons, has roughly four and a half million children under five but only about 900,000 were vaccinated at fixed vaccination posts. At the same time, they also gave measles and diphtheria-pertussis-tetanus (DPT) vaccine to selected children. Many were

vaccinated who wouldn't have been vaccinated otherwise.

A similar thing was done in El Salvador, just this year. I observed the program myself, but it reached an inadequate number of the total number of children who have to be protected. There's no substitute for a program in which the vaccine is either taken to the homes in sparsely populated areas or in fixed vaccination posts within easy walking distance or in densely populated regions.

Will this be done? It hasn't been done outside of the Western Hemisphere. Nothing comparable has been done in Africa or in Asia, but the Pan-American Health Organization has committed itself to eliminate and provide the conditions for continued control of poliomyelitis in Latin America within the next few years.

I believe it can be done by the use of this procedure, and I also believe the extent to which it will prove to be successful in Latin America may influence the adoption of this strategy in Africa and Asia. By developing comparable strategies for measles vaccine and DPT vaccine during the same national days of vaccination, I think that sooner or later it should be possible to achieve not only the rapid elimination and continued control of polio, but also of other vaccine-preventable diseases of childhood in the impoverished countries of Asia, Africa, and Latin America.

It will be important to have trained teams of specialists that would be able to work with governments who wish to try these annual vaccination days.

I would like to say a few words about what has become nationally publicized as a problem of people who have had poliomyelitis 20, 30, 40, 50, even 60 years ago. The problem of aggravation of existing paralysis or appearance of new paralysis has gone by various names which have conveyed, I think, misleading conceptions. To me, it is a definite condition in the sense that there is a new involvement of motor nerve cells in patients who have already lost many of the nerve cells by the action of polioviruses many years ago.

Every individual muscle fiber is innervated by a number of nerve cells from different levels of the spinal cord. On the basis of studies I carried out almost 50 years ago, I know that it is possible for polioviruses to wipe out the motor nerve cells at one level of the spinal cord, and have no clinical manifestations, no paralysis.

Supposing "something" or some other virus comes along later and destroys additional numbers of motor nerve cells, which in an individual who hasn't had polio before would have no recognizable paralysis. The combination of the nerve cells that have been destroyed with inapparent clinical manifestations decades ago, plus the new neurons that are destroyed by other viruses or by age, could give rise to new paralysis or aggravation of existing paralysis.

Professor Tomlinson's work has shown very well the loss of motor nerve cells with age, but he found that it begins at 60 years of age. Before that, you don't notice anything. Most of the patients are younger than 60, so it cannot account for all cases of the postpolio syndrome.

Viruses, other than the polioviruses, are still with us. The Coxsackie, the ECHO viruses, other enteroviruses, can destroy varying numbers of motor anterior horn cells in the spinal cord, which ordinarily may not produce apparent paralysis, but combined with a number of previously destroyed motor nerve cells, the effect could be new paralysis or aggravated paralysis of the postpolio syndrome.

There are many things included by some people in the postpolio syndrome that are not caused by new involvement of motor nerve cells. They're important to the people who have them, but this special postpolio paralysis syndrome should be limited to conditions attributable to loss of anterior horn cells. Proper studies should then be developed to give more reliable data on the magnitude of the problem, and what can or cannot be done about it.

## Questions & Answers

**QUESTION:** *Eight years ago, or less, in Indianapolis, a young mother contracted polio through the fecal matter of her child. Do you think the parents or the persons attending to the child's needs should be warned, if they were not immunized, that they, too, could come down with polio?*

**DR. SABIN:** There are many misconceptions about the cause of the small number of cases that are occurring whether without or with someone in the family having had polio vaccine. Virus from vaccinated children is being spread to other people everywhere. This is the basis for the elimination of polio from the United States, because the many millions who did not receive vaccine were vac-

nated by virtue of the fact that the vaccine virus was circulating in the community from the vaccinated ones.

There's no evidence that what the Indianapolis mother developed was caused by poliovirus. There are other conditions that simulate polio. There are viruses that are not poliovirus which are still circulating that cause polio. This is one of the dividends of the oral poliovirus vaccine, the immunization of the unvaccinated ones, and I think that people all over the country and the world come in contact with these vaccine strains and become immunized, but not paralyzed.

The killed virus vaccine (the Salk vaccine) does not really create resistance to reinfection. During the cold months of the past year, Finland, with only four or five mil-

lion population, which has been receiving only Salk vaccine for years, had an outbreak of polio caused by Type 3 poliovirus. They not only had eight cases, which would be equivalent to several hundred in this country, but laboratory tests on vaccinated, healthy children showed that 10 to 15% of them were disseminating the virulent poliovirus in the community. The whole population of Finland was given oral poliovirus vaccine to prevent even further dissemination during the hot weather.

It is unfortunate that in our country there is the tendency to have legal suits against the vaccine producers. We need legislation that would make it possible for manufacturers to fulfill the requirements of making vaccines without having to pay millions of dollars that are improperly awarded in legal suits.

**QUESTION:** *Is it necessary to be vaccinated only one time for the poliovirus?*

**DR. SABIN:** There are three different types of poliovirus, and there is a separate vaccine for each of these. In order to make it convenient for American pediatricians, they were all mixed together and instead of each one being given separately, a mixture of all three types is being given three times, in order to get better immunization against all of the three types. In areas where there has been no re-vaccination for 20 years or so, they're still immune. It's not necessary to re-vaccinate.

**QUESTION:** *Should someone who has had polio be vaccinated?*

**DR. SABIN:** I don't think they need to be vaccinated. The Type 1 poliovirus is responsible for 85 to 90% of paralytic cases, and the rarity, if any, of someone who's had paralytic polio once, getting it again from the two other types of virus is so slim that I don't think there's much of an indication for that.

**QUESTION:** *Is it true that there's a very, very low percentage of black people who have had polio?*

**DR. SABIN:** Not at all. As a matter of fact, in Africa, we have learned that during the last eight years they've had more paralytic polio than we had here in the United States before the vaccine era.

**QUESTION:** *What is the likelihood of another epidemic of polio occurring in the United States, since it's at epidemic proportion in Third World countries, and we are quite mobile in our travels?*

**DR. SABIN:** This issue has been dealt with by nature over a period of more than 20 years. The number of virulent paralyzing polioviruses that have come across the border from Mexico into the United States with families of little children, not only remaining in Texas and California, but spreading out, was very great. Yet, despite that, with the exception of a few rare cases right on the border, there have been no outbreaks of polio in the United States, nor evidence of dissemination.

# Polio Research

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## Lauro Halstead, M.D.

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When we look at what is known about the late effects of polio, it turns out that there is very little that has been published, and little that is known.

What is known is relatively recent. The 1983 conference played a significant role in helping to establish momentum in looking more carefully at some of the problems that are being experienced by post-polios. It was during the 1983 conference that the idea of holding a research symposium dealing with the late effects of polio was developed, and it was from the momentum established during that conference that we then went on to organize and hold the First International Research Symposium on the Late Effects of Polio in May 1984 in Warm Springs, Georgia.

That conference was small, intentionally. We had 35 researchers and clinicians, not only from this country, but

three or four other countries as well. The goals of that conference were to clarify what was known about the late effects of polio, as well as what was not known; to share information; to develop a research agenda. The stimulus for all of our discussions was the presentation of 18 scientific papers by people from all over the world.

What have we learned in the year since then? The research wheel is one that turns very slowly, and unfortunately, there are very few people around this country and around the world who have their shoulder to that wheel. In addition, the money which oils and greases that wheel is in very short supply. Few people are dedicating themselves to looking at these issues, and there are no established sources of funding. To get research done, we need public support, private support, and sustained funding.

I'm asked frequently, "How many people in the United States have paralytic polio?" I usually replied between

200,000 and 300,000, until several weeks ago, when I came across a source of information which provided a more accurate answer.

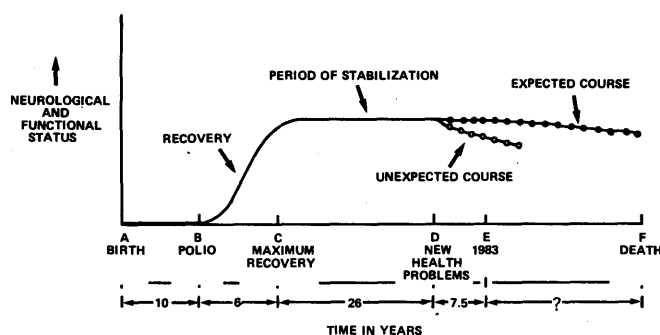
Every year the Public Health Service, through the National Center for Health Statistics, does a household survey on a random basis to assess various health problems around the country. In 1977, they asked, "How many people in this household are paralyzed?" If the answer to that question was yes, the next question was, "What was the cause?" From that survey, done by competent epidemiologists and statisticians and the basis for health care planning in this country, they determined there were 254,000 persons with paralytic polio living in this country in 1977.

What I find interesting about this figure and this study is that the largest cause of paralysis — as you would expect — is stroke, but the second largest cause of paralysis in this country is polio.

From Dr. Codd's work at Mayo Clinic, we know that approximately one in four are now experiencing new health problems. This means there are approximately 65,000 to 70,000 people in the United States with health problems possibly related to their prior polio. In our study, the most frequent problems reported were fatigue, joint pain, weakness in muscles that were previously affected, muscle pain, weakness in muscles that were thought to be unaffected by the original illness, and breathing difficulties.

Another part of our study looked at the length of the interval between onset of polio and the onset of new problems. In general, it is about 30 to 35 years. From these studies, we have been able to develop a clearer idea of the natural history of paralytic polio which is outlined in Figure 1.

**Figure 1**  
**CONCEPTUAL NEUROLOGICAL**  
**AND FUNCTIONAL PATTERN**  
**OF POLIO SURVIVORS**



The vertical line indicates neurological and functional ability. The horizontal line is a time line. So if we look at the interval from "A" to "B", which is from birth to onset of polio, the average age at onset of polio was 10 years based on a survey of 201 persons. Point "B" to Point "C", from polio to maximum neurological and functional recovery, was 6 years. Point "C" to Point "D", which is the period of neurological and function stability, was 26 years. Point "D" to Point "E", reflects the interval between the

onset of new health problems and the time of the questionnaire in 1983. In that group of respondents, the interval was 7.5 years.

In repeating this study in a larger group of 539 persons, the intervals were very similar except for the "D" to "E" interval. This was 12.3 years, which suggests that we're dealing with a fairly chronic and hopefully slow process.

The other thing which is of interest is that most people, including physicians, expected that after recovering from polio the polio survivors would only slowly begin to lose function as they got into their 60s and 70s as indicated in the top line of Figure 1 between "E" and "F". In fact, what I and many others have experienced is the bottom line with the open circles, the so-called unexpected course, being experienced by roughly 25%. We do not know how to draw the rest of that line. We don't have the data.

The crucial research topics for the future should continue to focus not only on medical issues, but on non-medical issues, as well. The medical issues should look at the causes of new weakness which have profound implications concerning the aging in the impaired nervous system. We can learn things which will be applicable to other disease processes, and perhaps aging itself. We need to investigate the best forms of managing the various types of new disabling conditions. We need more information about the best forms of exercise.

In the non-medical areas, we need more information in the psychosocial realm. At the post-polio clinic in Houston, the psychological problems of persons having to cope with new disability are equal to or greater than the medical problems.

Finally, we also need to look at the impact of these new disabilities on the family and work. We need to look at health care needs. This is a population which was not expected to have a whole new set of medical and social needs. Issues of financing, attendant care, transportation and independent living will all need to be addressed as we search for a better understanding of the causes of these neurological changes.

## **Mary Codd, M.D.**

During the last five years, when it became apparent that some post-polio individuals were experiencing new health problems, additional weakness and fatigue, and increasing difficulty with their daily activities, one question remained unanswered, to which Dr. Halstead has already alluded. The question is, "How many people, or what proportion of the survivors of the epidemic have these problems?" This is a question which has important health and planning implications.

To answer, there are two pieces of information that are essential. One is the knowledge of the number of persons who are living today who had polio in the past.

The second piece of vital information is to determine the present health status of all polio survivors nationwide. This piece of information is, indeed, more difficult to determine. One possible solution is to identify and follow selected groups of individuals, or those in defined geographic

areas. These studies are extremely useful in defining the clinical manifestations of the new health problems in post-polio individuals, but there are some problems associated with this type of study.

One is selection bias. Are we getting a biased view of post-polio problems by examining or following the example of post-polio individuals? Can the studies that are generated on these selected groups be generalized for the total population of polio survivors? An epidemiologic study of polio has been conducted at the Mayo Clinic in an attempt to address the frequency of post-polio syndrome relative to the total cohort of paralytic post-polios.

The Department of Medical Statistics and Epidemiology at the Mayo Clinic retains a data file containing medical records indexed by diagnosis since 1907. Documentation is complete for virtually the entire population of Olmsted County in Minnesota since that time, providing a unique opportunity to conduct population-based research. All persons in the population who contracted polio between the years of 1935 and 1955 were identified.

This time period encompassed the principle epidemic years of 1946, 1949, and 1952. There were 201 persons who had had paralytic polio in the 21-year period. They ranged in age from birth to 59 years with a median age of nine. There was a slight excess of females, and there were 23 people who died in the acute phase of the illness.

The remaining 178 persons formed the cohort for follow-up. Tracing these individuals revealed that seven had died in the subsequent years, four from causes apparently unrelated to polio, and three from causes related to their previous polio. Nineteen persons are on trace to date, and 152 were contactable. The Mayo questionnaire was circulated, and we received 142 replies, or a response rate of 93%.

Among the respondents, there were three people who were unwilling to participate. There were 109 who indicated that they had remained stable as far as their level of activity and muscle function since their maximal recovery from polio, and there were 30 who indicated deterioration since their maximal recovery.

A detailed telephone interview was then conducted with this group of 30 to ascertain more clearly the nature and extent of their disability. Sixty percent had increased fatigue, and 70% had complained of new muscle weakness. The majority of these stated that the new weakness was in muscles which had previously been affected by polio, though there were a few who said that the weakness was in muscles which were normal. Half of the group said that they had increased muscle cramps, muscle pain and atrophy, about a third complained of increased muscle twitching, and two thirds complained of increased joint pain. Seven people said that they had new or increased deformity.

Despite the increasing difficulties, it was surprising how few required additional ambulatory aids or assistance of any type. One person had to change occupation, and another had to cease because of the polio sequelae.

The interval from acute polio to the onset of new problems in this group ranged from 12 to 35 years, with a median of 25 years. Comparing this group with the stable group indicates that the follow-up period for both groups was almost identical, but the group with additional prob-

lems was older at follow-up and had taken longer to achieve their maximal recovery level.

We can say with some confidence that the population-based study of polio in Rochester circumvents the problem of selection bias, simply because of the ability to identify all affected individuals in a defined population. The 30 individuals identified who complained of increasing disability represent about 22% of the cohort followed.

The second problem encountered in epidemiologic studies of polio is that of case definition — the diagnostic criteria by which we should define a case, including a credible history of polio, a partial recovery of function, a minimum 10-year period of stabilization of this recovery following the acute polio, and subsequent development of progressive muscular weakness, for which there is no identifiable cause other than polio. Post-polio syndrome is a diagnosis of exclusion, i.e., additional symptoms in post-polio individuals which are not due to some other definable cause.

We need to standardize the criteria for diagnosis so uniformity can be achieved by groups in different centers, and results between centers can be compared. To ascertain the changes occurring over time in post-polio individuals, we need to validate self-reported symptoms by objective and quantitative reproducible measurements. This is the aim of a study presently being undertaken at the Mayo Clinic, for which we gratefully acknowledge the support of the Easter Seal Research Foundation.

The group of 20 which indicated deterioration are being examined to identify the exact nature of their disability and to determine if their disability is related to other correctable causes. We will compare them with a group of similar size who have remained stable since their recovery from polio. In addition to characterizing the nature of symptoms and providing an opportunity to study both groups more closely to gain some knowledge of the factors which influence deterioration, this study will provide baseline data and baseline evaluations from which and against which future evaluations can be compared.

Cross-sectional studies are very useful for gaining estimates of the occurrence of the problem. However, they're limited in predicting future developments, and the estimate that we have derived from the Mayo study of the proportion of individuals presently experiencing post-polio problems may change as the cohort gets a little older. It's only by continued surveillance that we can determine this.

One could argue that since the Mayo study is population-based, it can be generalized for the whole population of polio survivors. We can't be certain of this. The patterns of the polio epidemics varied in time and place, and it's possible that many factors influenced the outcome in groups and in individuals which varied according to the year and the location. However, as an estimate of the relative frequency of new health problems among paralytic polio survivors in the United States, it's probably the best estimate that is presently available.

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## Marinos Dalakas, M.D.

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The National Institutes of Neurological and Communicative Disorders and Stroke, National Institutes of Health, is a major research center where clinical and basic neurological research studies are conducted. We have been investigating patients with old poliomyelitis to understand the mechanism of the disease.

During the last four years, we have examined about 80 patients with old polio and we have studied a large number of them in detail with a series of histological, virological, electrophysiological and immunological studies. At the last meeting in 1983, we reported our preliminary studies with a small group of 17 patients who were referred to the NIH because of new symptoms. From the very first studies it became apparent that, according to the type of new neuromuscular symptoms which we subsequently defined, post-polio patients can be divided into two groups.

The first group includes patients with predominant musculoskeletal complaints such as joint pains, decreased stamina and endurance, easy fatigability, unsteady gait, and frequent falls. These patients, after adjustment of their braces or reduction of their work demands, appear to be again stable.

The second group of post-polio patients develop asymmetric and slowly progressive muscle weakness with wasting, fasciculations, and muscle pains usually in muscle groups of one or two limbs. We named this new weakness post-poliomyelitis progressive muscular atrophy (PPMA) and performed several virological, immunological, and electrophysiological studies in an attempt to understand the mechanism of the new disease.

PPMA occurs in muscle groups previously affected and fully or partially recovered or in muscles clinically unaffected during the acute disease. I must emphasize that PPMA is not distinctly uncommon and did not occur in a handful of patients as was mentioned in the press. We have seen at least 50 patients with PPMA during the last three years.

Concerning PPMA, there are four major issues that need to be addressed: the cause of the disease, the frequency, the rate of progression, and therapeutic interventions which could possibly stop the progression of the disease. With regard to the cause, we are in the process of analyzing a large number of patients by performing a series of immunological and virological studies in the blood and spinal fluid, and examining the affected muscles with electrophysiology or muscle biopsy. Our results will be reported in the near future when our analysis is completed.

In reference to how common the new symptoms are, I believe Dr. Codd's data will be very informative when her study is completed. I should emphasize, however, that our experience with mail surveys has been very disappointing. We have found that it is crucial to interview and examine the patients neurologically before an assessment about the exact nature of the clinical symptomatology is made. This is very relevant for the accuracy of epidemiological studies.

We have no specific therapy. Often, simply diagnosing the problem is very reassuring for the patient because he (she) knows what the disease is and stops hunting for

another doctor or another answer. Many of the patients we see are quite anxious or confused because no reasonable diagnosis was provided by their family doctor. Sometimes patients have been told that all their symptoms are psychological — "in their head" — or due to aging, explanations that often lack a sound scientific basis. For our patients we provide reassurance that this is a benign condition and we suggest specific rehabilitation therapy. We have treated one patient with interferon without success.

The last issue is how fast PPMA patients progress, and what a patient with PPMA should expect. In an attempt to answer this question, we decided to look again at patients who had been examined at the NIH several years ago for what appeared at that time to be PPMA as I defined it previously. These patients underwent the same studies that they had undergone several years ago, including a complete neurological evaluation, spinal fluid analysis, electromyographic studies, and virological studies in the serum and spinal fluid. Their mean age was about 55 years. The mean period after the acute polio when their first symptoms began was about 30 years. The average period from the time that they were first seen and examined at NIH until the time they were re-examined was about 11.6 years. Thus, we have an 11.6 year follow-up study of 12 such patients.

From the time the patients were first seen until they were examined again, their progression has been minimal, but variable. Some of the patients had a steadily progressive course, whereas others had a stepwise course with long periods of stability and then worsening. We have tried to calculate the degree of worsening that occurs year-to-year, according to neuromuscular function, based on a formula we have developed. From our data, it appears that on a year-to-year basis, PPMA patients progress so little that it is often difficult to come up with an accurate figure. The only way we were able to objectively appreciate some degree of worsening on clinical grounds was by using cumulative three-year periods. The average loss of neuromuscular function during that period is about three percent of the total (100%) muscle function. We have concluded from this follow-up study that PPMA is a benign form of new motor neuron deterioration that occurs in some patients with old polio with very minimal, slow, but often unpredictable, progression.

Although the worsening is very minimal, the degree of new disability is directly related to the patient's remaining residual muscle function. For someone who has already been left with very minimal function, a little more weakness may be significant for his (her) everyday activities. On the other hand, for a patient who has been left with minimal disability, the new worsening on a year-to-year basis, appears to have no significant impact on his (her) functional ability.

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# Questions & Answers

**QUESTION:** *Since there are only about 20 to 25% of the polios who do develop post-polio problems, have any studies been done to determine who would be predisposed to this?*

**DR. HALSTEAD:** In the questionnaire surveys we've done, the same factors were evident. Four variables seem to be predictive of people who are most likely to develop difficulty. They are: being hospitalized at onset, having paralysis of four limbs, being on a ventilator, and age at onset for those who were over 15 years of age, compared with those who were 15 or younger.

**DR. CODD:** I would go along with age at onset, and group the remainder into severity at onset.

**QUESTION:** *Dr. Codd commented that people she surveyed did not need new aids. Was there not a need for new aids, or did the people resist using new aids?*

**DR. CODD:** We're dealing with self-reports of both disability and the use of equipment or assistance of any type. This is one of the things that we need to verify when we do clinical studies and neurological evaluations.

**QUESTION:** *In your studies, have you looked at people without symptoms as to whether there's any indication that they might come up with problems? Are you looking at people who are not complaining of new problems?*

**DR. DALAKAS:** Yes. We are looking at those people, but we don't have long-term data on those people. We're doing another study on patients who do not have symptoms now, and this data will be available several years from now.

**DR. CODD:** I was struck by the similarity of symptoms among Dr. Halstead's surveyed population and the people we surveyed. However, there was a remarkable difference between those who reported to him that they were using additional assistance and those that we surveyed. We have

no way of determining what the reason is, but it would suggest that somebody is underestimating, or perhaps somebody else is slightly overestimating.

**QUESTION:** *Dr. Dalakas, were the letters you had received and the information that had gone to Congress and to NIH in support of funding helpful?*

**DR. DALAKAS:** They certainly are helpful. The suggestion I have is that the way to get funds through NIH or through the government is not by sending newspaper clippings. You can stimulate the physicians and make many other physicians aware of the problem, and they can write research proposals which can be funded.

**DR. MAYNARD:** I was glad to hear Dr. Dalakas' 12-year follow-up studies. It reinforces why "progressive," referring to this new entity, PPMA, is appropriate. Did I interpret your slide correctly, Mary Codd, that the group of 340 patients that did develop the new progressive weakness were the group that had a much longer recovery period from the onset of their acute polio to the period of stability of function and recovery? If that's accurate, would you comment on whether that is suggestive that the people who have to struggle to achieve a level of functioning are the people most vulnerable to this onset of new progressive weakness? It might reinforce the fact that the overexercise or overuse may predispose you to the new symptoms.

**DR. CODD:** Yes, you were correct in observing that the people who reported to us that they had deteriorated took significantly longer time to achieve their maximal recovery level. Those who told us that they had remained stable took an average two years, while those who indicated deterioration took an average nine years. Looking at these peoples' histories, that duration to achieve maximal recovery was certainly related to a number of factors, which, in turn, were related to severity at onset. One of those was repeated corrective procedures following which people had to have rehabilitative exercises, etc. It's also related to the actual extent of involvement at the acute stage.

# Living with a Ventilator

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## Ventilator Assisted Spinal Cord Injured

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### Kenneth Parsons, M.D.

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I have learned from coming to these conferences, and I've also had this experience in my practice in the past, that clients teach physicians who are willing to learn. Those physicians transmit what they've learned into the care of other clients, if those clients are willing to learn. We have teachers and learners involved in a cycle of sharing information.

Traumatic spinal cord injury is similar to polio, but it does differ from polio. First of all, we just heard the remarkable statistic that during the polio epidemics, there were about 20,000 new cases per year of paralytic polio in the United States. Our estimates of traumatic spinal cord injury are approximately 8 to 10,000 new cases per year.

As with polio survivors, a small portion of spinal cord injured end up having significant compromise of their respiration primarily because of the level of injury in the cervical region in the neck. Spinal cord injury is a problem of predominantly young people. Average age of onset is in the mid-20s. It is a sudden, devastating injury. Many people who have spinal cord injury are ventilator dependent from the very beginning. Others become ventilator dependent later on because of extension of their injury in their spinal cord. Some are weaned from the ventilator, some are not. Some have to return to the ventilator later on in life, but that number will be extremely small. There are a great many similarities between traumatic spinal cord injury and polio.

However, spinal cord injury occurs in a different situation. Often, about half of spinal cord injured patients are injured in motor vehicle accidents: high-speed, sudden deceleration against the car, or ejection from the car. Half of spinal cord injuries in motor vehicle accidents could be prevented if people would wear seat belts and shoulder harnesses that are already in the vehicle.

Many people with spinal cord injury have multiple injuries, not just broken back or broken neck. They have fractures of other bones, they may have a head injury, or they may have abdominal trauma, and so they're an emergency case. Therefore, tracheostomy is done very early after injury. There's a strong bias against tracheostomy among those of you who come to your respiratory problems by the route of polio, but remember that when we have to treat an abdominal problem, chest trauma, multiple other fractures, etc., there really isn't a very satisfactory negative pressure system that can be used. Also, many of these people have to undergo more than one operation after their injury, which also is difficult to do if someone is

not on a tracheostomy. Early tracheostomies help avoid complications in the larynx and the vocal cords.

Loss of sensation in spinal cord injury makes it different from polio. You might think about how your image of yourself would change if you didn't have sensation in certain areas of your body.

The automatic part of our nervous system that looks after temperature control, sweating, bladder control, bowel control, and sexual function changes after spinal cord injury, and makes management of spinal cord injury very challenging.

There really are five phases to rehabilitation, the first one being the acute care phase. The second one is mobilization, or getting out of bed. The third one is the equipment — ventilator, wheelchair, braces. The fourth one is discharge planning. The fifth one, your life, is the rest of your life. Hippocrates said, "It's the duty of the physician not only to do that which immediately belongs to him or her, but likewise, the physician should secure the cooperation of the sick, of those who are in attendance, and of all the external agents." The process of rehabilitation was well described.

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### W. H. Verduyn, M.D.

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John Cody was the first case we accepted. I had my training at Craig Hospital, where I was taught to manage ventilator dependent quads. When I came back to Iowa, I was going to send them to Craig, but they have a waiting period of three months, and I realized if I had to manage one for three months, I could get the quad home.

John Cody was with us for approximately four months, and then went home, went to school, and had some major changes in his life.

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### John Cody

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After a year in Columbia, Missouri, at TODCOMP, my wife and son and I split up. I came back to Dubuque with my certificate, but the employers saw the ventilator and asked, "How are you going to manage that?" I said, "It's quite simple. If my 16-year old brother can learn, anybody can learn." Needless to say, there were no jobs. I was lucky enough to be placed in an intermediate care nursing home. I've been going to college since. By the time I get my B.S., they'll have a lot harder time turning me down for a job.



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## Virginia Nelson, M.D.

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I'm at the University of Michigan, Mott Children's Hospital. We have a pediatric rehab unit for children and adolescents with all types of disabilities. Tom Partin was our first ventilator patient, and we all learned *from* Tom as well as *with* him.

There must be a team that works together with ventilator kids or adults in preparing them to go home. The team has to believe in home care and in independent living. The key to going home and to independent living is education. There is a lot to learn about the day-to-day care of spinal cord injury, especially about what can go wrong.

The emergency rooms or physicians in most communities, other than large centers, don't know, and are afraid of even routine colds or ear infections that kids with spinal cord injuries can have just like anybody else. The parents and kids who are old enough have to know everything there is to know about care. They have to be willing and able to train all care givers.

Our role in the hospital is to train parents and the initial set of care givers. In the process of rehab, Tom and his parents learned everything there was to know about his care and about the crises that were likely to come up.

One reality of education is that it takes a long time and nobody reimburses for it. It takes many hours to learn all the facets of care, no matter how willing and able people are to learn.

The process of education takes demonstration and supervision, having parents or care givers do it in the hospital setting and then do it at home. It takes a lot of written materials. In our system, one person is responsible for being the education coordinator for each patient, and generally, that's the primary nurse on the rehab unit. Each member of the team, however, will teach in his/her own particular area, whether it's the respiratory therapist or the physical therapist or the physician. I think physicians probably do the least amount of education of anybody on the team. In addition to being teachers, staff members must also be students, because each patient teaches the staff, too.

A big problem that we all have is, of course, funding. As I talk with people in other states, we probably have it fairly easy in Michigan. We've had tremendous support from the Division of Services to Crippled Children and from Medicaid. We were able to get the Michigan Medicaid Model Waiver written and approved. Tom was the first person who went home because of it two years ago. We are now in the process of having to get an adult waiver, because Tom is rapidly approaching the maximum age of 21.

Another key to discharge planning is equipment. It has to be portable, reliable, and we have to have fast, reliable service from the vendors. We also can learn from do-it-yourself equipment, and Tom will talk about some of the things that he and his family have figured out at home and now have taught us.

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## Tom Partin

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I went home on the first waiver. I'm luckier than John Cody, because I have a family that was willing to take me home, and they learned my care. I now go to school full-time. I mainstreamed my whole school.

My principal hated my guts at first. He was scared, he didn't know what to do or think, but now he's really accepted me. He even takes part in my care since I have to be catheterized. The kids don't know what to say because they're afraid they're going to hurt my feelings. I feel I have to start conversations, to let them know I'm just a person and the chair's just a thing. I'm still the same kid, just in a chair. It's not easy to do, but you get used to it. It's kind of fun in a way. Your old bullies don't bully you.

I was in the hospital for a long time, but I got the waiver to be able to go home, so things have worked out well. I hope the adult waiver is approved. I plan on going to college. I want to be a peer counselor if I can, but we'll see how things go. I have my ups and downs, just like everyone else. It's something you have to learn to live with, and when you get depressed, you've got to pull yourself out of it. You can't stay that way, otherwise you're not going to make it if you do. You have to try to be as normal as you can. People seem to be accepting me for me. Once you get them talking, then you can't shut them up, because they want to know. I like people to ask questions. That's what I like about little kids. They're not scared, and their mothers are very nice. I'm sure the polio people have the same problem.

I'm glad I'm here. It's my first time away since I got hurt. I'm really having a good time.

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## Oscar Schwartz, M.D.

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Spinal cord injured individuals who require machines to breathe are no different from other spinal cord injured persons. They need the same types of skills, education, and rehabilitation. Each must learn to cope with his/her own disability.

Ventilatory support should be used to build confidence and increase productivity. All too frequently ventilatory support is thought of in a derogatory way. The adjustment to a new lifestyle may be further hampered by a poor attitude. Health professionals may also have less than an optimal attitude, due to poor hospital and community based support services.

My first encounter with my friend Greg Franzen came through a phone conversation with his father. After rehabilitation as a ventilator assisted quadriplegic, Greg was searching for community based support services. He was frustrated. The rehabilitation center had completed its job: Greg had a good attitude, mobility skills, and a sense of independence — all he needed were attendant services.

I was pleased to acquire Greg as a patient, and since his discharge from the rehabilitation center, he has remained a friend.

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## Greg Franzen

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After my accident, I went to Rusk Rehabilitation Center in Columbia. It's comparable to Craig Rehabilitation. I think rehab's one of the most important things. You've got to get a good, positive attitude of yourself. That comes from the rehab, and if you don't get that, then everything after rehab won't fall into place — the will to go out in public,

to go to school, etc. With the technology today, the sky is the limit. You can do anything. There's really nothing you can't do — personal computers, architecture, engineering, etc. It can all be done through computers.

Attendant care is very important and very hard to find, but we were really fortunate in being able to find attendants. They're very few, and to find that very few is hard, and it takes a lot of money. We need new laws for funding so people can get a job so they won't have to rely on government.

The most frustrating thing is my ability to communicate. I can talk for three seconds, every three seconds, and that really limits you. You have to find choice words, and sometimes it doesn't come out right.

# Questions & Answers

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**QUESTION:** *Does the Medicaid waiver fund equipment and supplies, as well as attendant care? How do you teach attendants, or teach attendant management skills, to non-family members or non-professionals in addressing the needs of ventilator dependent persons?*

**DR. NELSON:** When we have somebody who is a candidate for the waiver, we get together a package that includes the total cost for a month's care in the hospital. We then put together what is planned care in the home, including however many hours of attendant care we might need, any nursing visits, supplies, equipment rental. That is sent to the waiver office, along with the total care plan. Generally, equipment such as wheelchairs is funded by the state crippled children's agency, rather than by the waiver. Disposable equipment and ventilators (which our kids rent, not purchase) are funded under the Medicaid waiver.

We have to prove that it's cheaper in the home setting than it is in the hospital. Even with 24 hours of LPN care, it's cheaper at home than it is in the hospital, any way you look at it. On the first eight ventilator kids sent home in Michigan, there was a 60% savings averaged over the cost

in the hospital. The waiver is for people who do not have insurance that will cover them at home, and who are not Medicaid eligible, and therefore, don't have payment for services at home. The waiver does not pay parents for delivering care in the event that attendants can't be found.

**DR. VERDUYN:** In Iowa, we have had a tremendous problem getting waivers. We have fought and fought and fought, and they won't give it. We have an in-home health program in which the money will go to the client who then can hire mother, father, or anyone else. This is somewhat of a solution. There is a different issue between adults and young people. The real problem in funding for care givers is that we as a society seem to think that the significant other, husband, or wife, is an automatic care taker.

**MR. CODY:** I think the reason my marriage failed was that I relied on one person. Now the nursing home is sort of a way out for me, because there are three separate shifts. Everyone gets to go home at the end of each. If people are going to be able to move in with their parents, or with their mates, they're going to have to have extra outside help so these family members can get away. The rest of the family has to have a life away from the injured person, too.

# Ventilator Assisted Children

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## A. Joanne Gates, M.D.

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Since I've gotten involved in this and found out about polio survivors, I want you to know what a role model you've been for me and the children to whom I supply care. It helps to be able to tell them and their families that they can succeed, that other people have done it, and that there are other people to help. We're just now getting a network going between our polio survivors and our children. They've offered to come and help the families and teach the kids all the little tricks they've learned.

Federal funding developed the programs, not to supply care, but to develop the systems to help ventilator assisted children get out of the hospital. It's important to recognize the gap between now and the time that everyone with polio went home on ventilators, because there's an attitude problem. Ventilators are for intensive care units, and the only thing you can use ventilators for is to help someone survive an acute illness, but you don't send someone home with one. Anything's better than a ventilator. There's an ego need in physicians, recently trained nurses, recently trained respiratory therapists, to wean from the ventilators, even though the patient be a C-1 quad or have progressive neuromuscular disease. There is that need to wean, and I've chosen to call it the need to teach the patient to tolerate less than optimal conditions.

Allen Goldberg has been partially responsible for developing the definition of optimal ventilation. That means the ability to not only ventilate, but to grow and develop and think about other things than where your next breath is coming from. That's what we try to do for children — to re-define who needs ventilatory assistance.

In our program, we have three basic groups of children. We have quads, traumatic quads and one who was a victim of child abuse. We have congenital anomalies, children who, through a congenital defect, diaphragmatic, pulmonary or otherwise, are victims of respiratory insufficiency. This includes premature babies who are victims of our technology, and in fact, have abnormal lungs, bronchopulmonary dysplasia (BPD). They are victims of the very machinery that saved them. The trauma from the ventilation, the high concentrations of oxygen that are necessary for their survival, have permanently injured their lungs to one degree or another. How much they recover depends on how far they got down the road, but they do have the same problem with it taking one to five or ten years for them to find out how far they're going to come back. In the meantime, they need some help.

A third group of patients is the neuromuscularly impaired patients, those with progressive neuromuscular disease. Five or ten years ago, these people all died. The thought of offering them ventilatory assistance was anathema. If you couldn't breathe on your own, you died. Then one day somebody asked, "How is somebody with Werdnig-Hoffman different from somebody who's quadriplegic?" They're still bright, they still enjoy life, they bring a lot of pleasure to their friends and their family, so what's the difference?

One of the things I'm proudest about in Louisiana is our educational program. We now have four children in school. Most of the rest of them are too young to even be in school, but the educational system, as far as taking them back in their regular environment, has been magnificent.

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## Allen Goldberg, M.D.

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From the point of view of institutional providers, more ventilator assisted children (beneficiaries of our technological progress, graduates of our regional intensive care units) are "living" in medical acute care centers. We have made little headway in developing respiratory rehabilitation as we know exists in centers like Goldwater, T.I.R.R., Rancho, Craig, etc. There are inadequate vertical and horizontal interactions among existing health care resources.

In Illinois, progress is being made with the development of transitional care in chronic care institutions such as LaRabida Children's Hospital and Research Center. In addition, community based options are being considered, such as the Marklund Home, for youngsters with developmental disability.

At Children's Memorial Hospital, the Ventilator Dependent Discharge Program has provided a good model for the discharge to home of ventilator assisted children and their families. We are attempting to coordinate the private, public, and voluntary sectors; community support resources; service organizations; and reimbursement agencies. Organizations are beginning to be willing to provide more and more services to the ventilator assisted child and family. However, what is available is still disorganized, and people don't know where to find what is there. The community options we need are not yet in place. There is no uniform approach for reimbursement. The government has suggested waivers from existing policies, but sometimes these waivers create more bureaucratic problems than existed in the first place. However, they have enabled many persons to go home who otherwise would still be in institutions.

A quality assurance system is essential. We do not know the outcomes of children and families at home, and, as a result, we do not know if we have a program that has met the needs of the consumer and the reality of cost-containment. For continued progress, family members must take on new self-help roles and become more involved in the system being put in place.

The Children's Home Health Network of Illinois is making an assessment of the needs of professionals, consumers, and organizations in order to design a workable home care model. All concerned people must become involved and determine their own needs — not have them prescribed for them. They can help plan, implement, and evaluate a realistic program in which they can feel a sense of ownership.

# Muscular Dystrophy and Mechanical Ventilation

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**Agatha Colbert, M.D.**

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Duchenne muscular dystrophy is an inherited disease. Females are carriers, and males manifest the disease. The course of the disease is stereotypic. Children are usually diagnosed at about three years of age, presenting with weakness primarily in the hip girdle musculature. They are generally in a wheelchair by ten years. The average age of death is 18, although some live to their mid 20s.

As Dr. Gates mentioned, in the past these particular boys succumbed to an early death because of the natural course of the disease, usually dying of respiratory failure. In our age of modern technology, with the availability of so many different types of ventilators, life can be prolonged without major inconveniences in life style. At Tufts, we endeavored to explore the options for our patients with muscular dystrophy and their families.

Review of the literature revealed only four articles advocating the use of ventilators for patients with Duchenne muscular dystrophy (Bach, Alexander, Curran, Rideau). In 1979, Ernie Johnson's group from Ohio State, with one of the authors, Donna Stauch, reported on their patients who were provided with a combination of negative pressure and positive pressure devices. They documented that people with Duchenne dystrophy were able to survive some four to eight years after the onset of respiratory failure and the quality of their life was meaningful.

Another article by Dr. Curran, Lakeville Hospital in Massachusetts, discussed the use of negative pressure ventilators, primarily the iron lung. (Thanks to Sunny Weingarten, that iron lung now is being changed to the fiberglass porta-lung, which is more convenient to transport.) Dr. Curran showed that these kids could sleep in an iron lung eight hours a night, get up the next day, feel refreshed, and go to school in their powered wheelchairs, unencumbered by any other respiratory equipment. Some of these patients are now ten years post onset of respiratory failure and are still utilizing negative pressure ventilators only. (For school age children, there is a definite advantage to not having a tracheostomy because schools, at least in Massachusetts, are ill-equipped for managing trach care.)

Doctors Bach and Alba reported that Duchenne muscular dystrophy patients could live more than 20 years on respiratory aids in the community. Most of them were using either mouthpieces or tracheostomies.

Doctor Rideau from France poignantly states that if we let patients with Duchenne muscular dystrophy die of respiratory failure, we have failed severely in our medical management. However, this opinion is not held by all the medical community.

In reviewing the literature, there are at least four or five other prominent health providers who care for Duchenne muscular dystrophy patients, who feel strongly that antibiotics, chest physical therapy, and other supportive treatment should be provided, but that ventilators should be avoided at all cost.

Having done the literature search, we wanted to find out the practice of prescribing for individuals with neuromuscular disease in the United States. A questionnaire was sent to 240 Muscular Dystrophy Association clinics in the United States, since the vast majority of people with Duchenne muscular dystrophy are cared for in these clinics.

We received 132 responses, a 55% response rate. We asked, "Do you routinely provide ventilatory support systems for your patients with neuromuscular diseases?" The answers were variable. Twenty-four percent said they routinely provide the support. The other 43% said they do so "under certain circumstances," such as, "depends on the disease, never as an outpatient, never in the home, non-invasive only." Some said "only negative pressure." Others said, "Only positive pressure devices. The patient is given the choice, only for acute disorders, not on a chronic basis."

The majority of physicians who said, "under certain conditions," were not providing ventilators for individuals with ALS, Duchenne muscular dystrophy, or other progressive diseases.

In Boston, where there are three major medical schools and several teaching hospitals, we found no consensus among the MDA clinic directors with regard to prescribing ventilators. One center, for example, offers ventilatory support to any patient who wants it. They try to provide as much information as possible regarding the use of a ventilator and its impact on the overall functioning of the family unit.

Another major teaching hospital does not tell families that there is ventilatory support available, and actively discourages people if they ask for it.

The next step of our study was to look at the individuals for whom ventilatory aids have been provided, i.e., to talk with them and their families to determine what it was like and whether it was worth it. Jessica Robins-Miller and Nancy Schock designed a questionnaire with which to interview 15 persons and families who were using ventilators. The majority were patients with Duchenne muscular dystrophy, but there was also an individual with muscular atrophy and one with myotubular myopathy — all progressive diseases.

They found that the decision to use a ventilator was unanimously made by the parents rather than the patients, because the individuals involved were legally under age. Many parents felt they did not have much of a choice. The children would gradually manifest symptoms of under-ventilation, i.e., trouble sleeping at night, headaches, and occasional nightmares. It came on fairly gradually, but from the time they presented to the clinic and the diagnosis of respiratory failure was made, two weeks was all that was available to decide whether they wished to prolong life or let the disease take its natural course. Some parents said, "The choice is either a respirator or death, and I cannot let my child die."

None of them felt that they had permission to say, "No, we are opting not to prolong life," because none of the medical community said, "We will support you in your decision, we will help you in the dying process." Physicians have a hard time saying, "I will help you die." It is a lot easier to say, "I will do everything I can to keep you alive."

On the other hand, the individuals with muscular dystrophy felt wonderful when they were provided with ventilatory support. One young man said, "It's breathing like you never breathed before. You just feel like a million dollars." He could sleep all night without requiring to be turned. The iron lung completely rests the muscles of respiration at night, so that during the daytime, many patients need no ventilatory support and still feel terrific.

The problem with Duchenne muscular dystrophy, however, is that it is a progressive disease, and as time goes on, more time is needed on the ventilator. The disease progresses in other ways with increasing loss of function in the upper extremities. More contractures develop along with further progression of scoliosis; there are also more problems with pain. Several patients cannot sit or lie down and are uncomfortable doing most activities because of their severe scoliosis. Pre-existent cardiac problems may become symptomatic. There are also complaints of gastrointestinal problems.

Parents are overburdened because the children are not eligible for personal care attendants, being for the most part under 18 years of age. Many parents have expressed how stressful it is on marriage and family life.

When the children graduate from high school, most of them lose the stamina and the energy to do anything more. Some of our patients have tried to go to college, but lacked the physical energy to sustain that endeavor. They then became socially isolated with all their friends going off to school.

Ventilators are being prescribed for persons with progressive diseases throughout the United States, but there is no consensus of opinion as to who should receive ventilatory support. There is no established decision making

about when to use or not to use a ventilator. There is no standard protocol telling what is the best ventilator for an individual. We know very little about what happens in the natural course of muscular dystrophy once life has been prolonged.

We are studying the quality of life for persons who are on ventilators. We now have 30 people with Duchenne muscular dystrophy who are living on ventilators; Dr. Alba has about 25. We plan to interview all of the individuals in order to assess the quality of their lives and document their continuing health problems. We are putting together an educational brochure for families and individuals to help prepare them for the stage of respiratory failure, to allow them more time and information in which to make that critical decision of extending life with a ventilator.

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# Independent Living: American Versus European Models

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## Gerben DeJong, Ph.D.

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The American independent living movement and the policy prescriptions implicit in that movement tend to be badly misunderstood when viewed from the perspective of West European (Scandinavia, The Netherlands, Belgium, Germany, France, and the United Kingdom) social policy. Much of this misunderstanding tends to be self-serving. The misunderstanding comes from people from other countries who buck, or who find difficulty in communicat-

ing their ideas back home with their bureaucratic counterparts, with their service delivery professionals, and others.

Early in the American independent living movement, there was a perception abroad that this movement was somehow a radical and leftist movement, because the movement made a number of demands for a more aggressive government role in issues and matters that affected their lives, especially in financing new services, in regulations diminishing architectural barriers, in fostering new modes of accessible transportation, and in encouraging affirmative action.

The government has been, and is viewed as, a positive and necessary force in the struggle for equal opportunity and access to the mainstream of American life. This view of the American independent living movement as a kind of radical or a quasi-leftist movement is also reflected in the heat that the movement took from the Reagan Administration, especially during the early days.

Few of us can forget the vitriolic debate about architectural accessibility and how the Architectural and Transportation Barriers Compliance Board was hotly divided about the debate, separating the consumer point of view from the point of view of the appointees made by the Reagan Administration. We can also see the Reagan Administration's hostility toward persons with disabilities, especially in the Social Security Program and the intensified review process that resulted in many people being denied benefits under the Social Security Act.

Despite the fact that the independent living movement has been painted as leftist by certain ideologues in this country, I have argued that the values of the independent living movement are very much in tune with the dominant values of American political and economic life and with the free market pluralist ideology that has dominated American economic life to this time. With free market theory comes a concept of an autonomous, independent individual competing in the marketplace.

By pluralist ideology, I mean interest group politics, the right of every political interest group to compete in the marketplace.

Thus, in my view, the American independent living movement has some affinity with the individualism of American culture. This is extremely well illustrated in the attendant care model in this country where a person with a disability can, on his or her own, recruit, hire, manage, pay, and fire his or her own attendant.

This affinity with individualism is disturbing to non-Americans. It's reminiscent of the do-it-yourself bootstrap philosophy and the anti-welfare state mentality that characterizes much of the American political right. It is ironic that the movement is perceived as radical and sometimes leftist in America, yet, the same movement is perceived as individualist and rightist in Western Europe.

My characterization of the independent living movement as having a significant affinity with free market and pluralist thinking should not be construed as an endorsement of unbridled individualism. Despite its affinity with conventional American values, and despite the fact that the American independent living movement was spawned in the individualist, self-help culture of America, the independent living movement is not an untamed evangelist for individualism, nor is its implicit support of free market, pluralist thinking an unqualified one.

First, the movement's emphasis on self-help and self-reliance has a communal, as well as an individual, component in the form of community support, mutual responsibility, and disability solidarity.

Second, the movement has discounted the competitive market as a sole standard of self-worth, and promoted self-esteem through community action and support.

Third, the movement has insisted that much of the pathology is in the environment, not the individual. It has steered away from destructive victim blaming.

Fourth, the movement has steered away from destructive political competition that has characterized disability politics in the past. It has formed new coalitions, or been an important instrument in the development of those coalitions, such as the American Coalition of Citizens With Disabilities, and groups such as the League of Disabled Voters.

Why have some West Europeans seized on individualism as the means of discrediting the independent living movement? Why have Europeans taken note of this individualistic character of the independent living movement when there are other features?

West European social policy has been guided by a set of principles, concepts, features, that put West Europeans in a somewhat different frame of mind. Western European social policy is based on the principles of social democracy.

The first and most important concept that undergirds West European social policy and West European social democracy is a concept of solidarity, namely that all groups must share — wage earners and non-wage earners, young and old, disabled and nondisabled. All share a common bond that is indispensable to social well-being, that society is no better than the well-being of its "weakest members." Thus, when there are cutbacks, to a large extent, they are more equally distributed than in America, and cutbacks in disability benefits generally are proportional to cutbacks in wages and other social benefits.

The second principle is the principle of risk-bearing. Society pools its resources to protect against the contingencies of aging, illness, disability, and death. Risk-sharing is part of Europe's social insurance programs. Services which are financed in America on an ad hoc basis, such as adapted housing, durable medical equipment, transportation, etc., are financed in Europe to a much larger extent through its mainline social insurance programs.

Third is the concept of a social minimum, a nationally recognized minimum standard of living by which social policy is formed and determined. It not only guides wage policy, but also significantly guides the various income benefits that are available to people with disabilities, and also guides the tax policy as well.

The fourth attribute or feature of West European social democracy is the concern for the distributional impact of any policy or program. As labor productivity increases, there is a concern about how that productivity is going to be shared with all members of society. When unemployment increases, there's greater concern about how the effects of unemployment are going to be distributed through society. There is a similar concern for income benefits and tax policies. Holland is very much preoccupied with this concept of a social minimum and how it is determined and shaped.

The fifth concept is the concept of equality. In America, the concept of equality is really an equality of opportunity. In Western Europe, there's more concern not with equality of opportunity, but with equality of outcome — how people end up at the finish line, not how people start at the starting line.

In America, the unit of observation is the individual. Equality is based on how various individuals can be compared with one another. In Western Europe, the unit of observation is much more the family, and this again is reflected in social and tax policy throughout.

The sixth principle or concept or feature of Western European social democracy is its policy making process. Western Europe uses consensus forming groups, umbrella organizations. Parliament, rather than an initiator of policy, tends to be more a ratifier of policy. This can be contrasted with the American policy making process where each group is left to fend for itself.

Given these six principles, features, concepts describing Western European social policy, American social policy by comparison does seem individualistic, perhaps self-destructive, and guaranteed to produce unequal outcomes. To a large extent this is true, but to criticize the American independent living movement as participating in destructive individualism is both misleading and unfair.

One of the things I've observed often in Europe is an inherent, almost knee-jerk tendency to dismiss anything American, particularly in social policy, as individualistic. I find it a codeword by which to discredit much of what is being done in this country, and a reductionist critique of Americans. I also detect a certain bit of European intellectual snobbery. West Europeans tend to overlook that the American independent living movement is a small movement within a much larger social, political and economic context. To have some credibility, the movement has had to make some connection with the value system of a larger culture, or simply find itself politically isolated and politically impotent.

The charge of individualism is a ruse — a convenient way in which welfare state professionals can take cover. The independent living movement is not anti-welfare state, nor is it anti-professional, but it is anti-professionalism. That is an important distinction.

What the independent living movement seeks to do is to redefine the professional and consumer relationship. Among West European service providers, there is a great deal of professional self-interest in the charge of individualism. In spite of the advanced nature of the concepts and principles that guide West European social policy, European professional attitudes toward disabled persons are patronizing and paternalistic.

The independent living movement should not be viewed simply as a movement for individual independence, but as a movement for group independence. It is an emancipation movement — emancipation from social control, paternalism, patronization, and professionalism. The question remains whether or not the ideals and ideas of the American independent living movement can be transplanted to other countries.

The argument goes something like this: "the independent living movement could only have been spawned in the self-help culture of America. We in Europe have the welfare state, we take care of our disabled, therefore, the independent living movement is not relevant here." It's another way of attempting to discredit the American independent living movement.

Europeans have a much greater degree of ideological awareness than Americans. There is a great need to pin down any phenomena or service delivery system or social movement on an ideological continuum. Then individuals can determine their level of comfort with that particular movement based on their own political philosophy.

The American independent living movement is hard

to pin down ideologically. Seven or eight years ago, when I wrote about the independent living movement's affinity with a free market pluralist ideology, I may have done the movement a disservice. My point at that time was to counter the thesis that the independent living movement was a radical or leftist movement. It's interesting that both Judy Heumann and Justin Dart can coexist in the same movement. It speaks to the ideological resilience of the American independent living movement. By discrediting the movement's ideology, many European professionals are trying to discredit the legitimate aspirations of disabled persons.

Marilyn Ferguson published *The Aquarian Conspiracy: Personal and Social Transformation in the 1980s*. She conducted a survey and asked the respondents to categorize themselves politically on a questionnaire. However, many of the respondents "expressed great frustration. Some checked off every box. 'Radical, Liberal, Centrist, Conservative, and With Apologies.' Some drew arrows across the spectrum. Others wrote marginal notes, 'Liberal, but . . . Radical in some issues, conservative in others. These categories don't apply. Radical, but not in the usual sense. Choice is too linear. Old categories are useless.'"

Ferguson quotes a British-born economist in her survey who drew a circular spectrum saying that the United States has a reservoir of flexibility in its political system: "It has not yet polarized into the sterile left-right axis now compounding Britain's problems. The forces in the United States are circular."

Regardless of ideology, there are certain needs that are fundamental to human existence. We may quibble as to how these services are to be rendered or to be provided, but they transcend ideology, whether one is an individualist or a libertarian or a conservative or a liberal or a collectivist or a socialist or a Rawlsian or a Marxist. None of these ideologies have dealt with the issues of independent living and environmental accessibility head-on.

The creative ideas of Fokus in Sweden, of Het Dorp in Holland 20 and 30 years ago came out of the social democracies of Western Europe. Yet, some of the most creative ideas with respect to disability and environmental accessibility are coming from a culture that has been characterized as individualistic.

Much of the European critique is sterile, and does not speak to the ideological resilience of the American independent living movement.

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## **SOUTH AFRICA: Kathy Jagoe**

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South Africa has perhaps been eclectic in its disability movement, drawing from both America and Europe. I pay tribute to people like Judy Heumann, Ed Roberts, and Irv Zola, who have been a big influence on myself and others, and special tribute to Gerben Dejong on the theoretical side for the influence he's had on my work as a lecturer in the disability field, and as an activist in South Africa.

The disability movement in South Africa probably emerged in 1981. The national organization, Disabled People South Africa (DPSA), was launched in 1983. (It was formally constituted last year.) It is made up of self-help



groups and individual people who are disabled, and it's a cross-disability group (which we're very insistent about in South Africa), cross-racial, and it crosses all ages. The group has decided not to align itself with any political party. It is totally against violence of any form because of the disabling effects of violence.

Disabled People South Africa (DPSA) as an organization has not been accepted into Disabled Peoples' International because of the politics of the South African Government. I understand ideologically this rejection of South Africa, and rejection of the disability movement in South Africa. While I can accept the discrimination and the rejection of myself as a white South African, I feel strongly that my black colleagues are also being discriminated against. I find this very uncomfortable, especially coming from other disabled activists who talk about "unity" as "strength" and, who, while fighting against the discrimination experienced in society against themselves, openly discriminate against others.

Along with a number of other activists in South Africa, I am not prepared to wait for the revolution to be over before we look at disability rights. We don't align ourselves with any political movement, and we certainly don't align ourselves with the present South African government. We don't accept money from the government, but where it's needed, we will pressurize and work with the government in order to get facilities for disabled people.

We've been fighting for four years in our country for some kind of recognition of accessibility requirement in the building regulations. On March 1, 1985, building regulations were published in our country excluding any mention of disabled people, and this was after a four-year struggle. Disabled People South Africa then sent a telegram every two weeks to the government demanding an interview. At last we could do this from a national organization (and a number of us did it as individuals), and the day before I left for this conference, the government called three of us to a meeting, and in front of us, told the South African Bureau of Standards (SABS) not only to re-look at the regulations on barrier free design, but that they should do it together with DPSA's Technical Action Group and not simply give us a finished document. This was an exciting breakthrough.

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### **UNITED STATES: Ed Roberts**

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People want to decide what they are going to do with their lives. They want to choose their own lifestyles and don't want to be forced to be in a nursing home or an institution. They want to choose where to live, whether it be in a group home with other disabled people, in the community with family, or independently. This concept of choice is what brings people together and unites them around independent living.

Independent living states that there is the right to equal opportunity and the right to make choices in an environment that is not patronizing. Independent living centers are geared to helping people move from dependency towards taking charge of their own lives. Programs in the past have fundamentally excluded people with disabilities

from leadership roles, but the independent living movement took the stand that its programs would have disabled people running them, especially as directors and executive staff. We recognized that it was reverse discrimination, but it was necessary since there were so few that were able to get administrative experience. We were role models showing other people with disabilities that if we could do it, they too could do it. I recognize that people without disabilities contribute and are an important part of independent living. If we truly believe in equality, then we have to do this together, but until the time comes when there is equality, I will continue to believe that we should make sure that people with disabilities have more than an equal opportunity to take on these programs and learn leadership.

It is a disgrace that there is no national health plan. The independent living movement had to struggle to get what it has and so it has become a strong voice. The consumer movement must move society towards a national health plan and a long-term care program.

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### **UNITED STATES: Phyllis Rubinfeld, Ed.D.**

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As president of the American Coalition of Citizens with Disabilities, I see a similarity between the poverty programs of the 1960s, the way in which they were funded, and the independent living movement of today. I believe the government really never meant for the poverty programs to be successful. The independent living movement is receiving government funding and I don't believe that the government really wants the centers or disabled people to become so independent that they would be a significant force to politically and systematically change the current structure of the country. When the centers' funding is cut, I don't hear about other centers going out in their support. They're afraid to bite the hand that feeds them.

As soon as a center starts to focus on civil rights issues, it will systematically be reduced, and eventually unable to function. There will always have to be a certain number to give the image that that, indeed, is not what the government is doing.

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### **WEST GERMANY: August Rüggeberg**

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The well organized social welfare system in many European countries tends to reduce the consciousness of disabled people toward taking risks.

Many Europeans, especially disabled Europeans, have been exposed to vast amounts of patronizing care by professionals and institutions, and tend to lose the motivation for risk-taking. They strive for security instead of growth, for being cared for instead of taking their own responsibility, although they would like consumer control. Many of them are in a fundamental conflict.

What is needed is to demonstrate that one can take responsibility for oneself in practical everyday life without necessarily being afraid that everything will go wrong



from then on. This is why I think it's very useful to send as many disabled people as possible from Europe to America to see how it works here.

I don't feel personally that the attendant care model is too individualistic, but this is what makes people, for instance, in Germany, skeptical about the attendant care model, because we have the attendant care model in an even more extreme form.

We have conscientious objectors who have to do civil service instead of service in the army. There are several thousands of them who work in attendant care services. I often hear that it is such a vast amount of work to hire one's own attendant, to teach him what to do, to criticise him, to organize the time schedule, etc.

Patronizing professionalism is one of the most outstanding problems hindering disabled people in Germany in achieving more control over their own situations. Disabled people in America have to fight also professionalism, but professionally qualified disabled people running independent living centers would guarantee that the consumers can gain control of their life situations.

As the independent living movement, and especially independent living centers, tend to be more professionally organized, as services tend to be rendered by professionally paid disabled people, there is a danger that a new form of professionalism can develop. As long as people like Ed Roberts or Judy Heumann or Max Starkloff or other people of the first generation who have fought in very intense personal struggles remain, this danger is not such a danger yet. However, other generations will take over, and I'm very skeptical if the peer principle will guarantee this movement to go on as it started.

One important question we should be discussing in the future is the involvement of dedicated consumers and volunteers in the movement, not on a paid basis, but people who are concerned with the problems we have not yet solved, people who are politically conscious and strong enough to control professionalism.

Ideas like accessibility or care in the community or certain forms of social rights that the American independent living movement has been striving for have not been invented in this country. There are lots of people who know about accessibility in Europe, and there are many people who strive for equality between the disabled and nondisabled, and partnership and friendship. It could be a barrier in communication between Europe and the independent living movement in America if there arises a feeling in Europe that the Americans think they're the inventors of all these ideas.

European disability movements or organizations have also stressed the principle of disabled people taking control of the organizations as in America, however, some critical qualifications have to be made. There are many disabled people whom I wouldn't like to see as director of an independent living center, and there are many nondisabled people who would be actively engaged for the interests of disabled persons, not in a paternalistic way. It couldn't be illustrated better than by pointing to Gini Laurie. I would like to question this total generalization of

disabled people running their own organizations. Could this not imply an element of a new self-segregation?

Disabled and nondisabled people in the independent living movement can work together in partnership.

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## DENMARK: Anne Isberg

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Denmark has socialized medicine. Everything is paid — from going to a hospital or a nursing home or a rest home — through taxes. A hospital bed costs about \$300 a day, a place at a rest home costs about \$100 a day, and a place at a nursing home costs between \$100-300 a day. Not considering the human aspects, society has a tremendous interest in keeping people out of institutions and hospitals in order to cut down deficits on the national budget. Efforts are taken to keep people in their homes as long as possible.

To achieve this, society provides an attendant care program. In order to qualify for attendant care you have to be above 80 years old or have a medical prescription or a medical prescription plus a social evaluation. The attendant care program is divided in two groups: 1) domestic attendant care and 2) special attendant care.

**1) Domestic attendant care** attends the elderly. One automatically qualifies if one is above 80 years old. It takes a prescription for disabled persons, people who have just been dismissed from hospitals, or people who can make it at home with only a little extra help.

The domestic attendants are employed by the counties, and are trained and instructed by the counties. The attendants serve in certain areas and are organized from local offices. Local offices are to be found all over the country and usually it takes less than a week to set up an attendant care arrangement of this kind.

If one's income amounts to more than the social security, one will have to refund the local administration office part of the attendant care expense. The refund is graduated according to income but payment cannot exceed \$4 an hour even though the attendants are costing about \$6 an hour.

The attendant is to assist with ordinary household operations: light cleaning, laundry, cooking, shopping, light assistance to personal care, etc. Normally a person is provided with this kind of attendant care two to three times a week, two to three hours at a time.

If the local office for attendant care cannot provide an attendant at the time a family needs it, there is a possibility for giving the family an allotment for domestic help that the family itself employs. This possibility exists in the law, but I have never heard of it being practised.

**2) Special attendant care** came about after the polio epidemic in 1952. There were still several patients with severe respiratory insufficiency left in the hospital in 1957. Most of these were children. They weren't sick but they needed access to help 24 hours a day in case of failure in their respirators or secretion in their lungs.

Because of these non-sick hospital polio patients, a program was started so that the patients could be dismissed from the hospital to live in their own homes. The

family could hire attendants and these were paid by a government office in a specialized respiratory nursing home. The attendants were hired, trained, instructed, and fired by the family, but paid by the nursing home. The nursing home acted as a back-up for the availability of attendants. Also, it could relieve a family during its vacations.

To a certain extent, this program is still in effect. Today the program is for everybody with respiratory insufficiency. Respiratory problems in Denmark are not treated with medicated inhalations, rocking beds, pneumobelts, mouthpieces, cuirasses or iron lungs. Either one can make it on one's own or one has a tracheotomy with all the related problems.

Attendant care for persons with respiratory problems is provided through A) professional attendant care and B) normal attendant care.

**A. Professional attendant care**, prescribed by a physician, is provided by medical students. The students are sent to the home, and the family has no say in who is coming and what they shall do. These professional attendants are paid by a hospital and are under the supervision of a physician.

This way is not used very often, and it came into effect in 1977 only under the greatest protest from the highly specialized respiratory physician, Dr. Sund Kristensen at University Hospital of Copenhagen. Dr. Sund Kristensen does not consider users of respirators as being sick.

**B. Normal attendant care** is organized very much like the original program in 1957.

A tracheotomy and the use of a respirator almost automatically qualifies a person for 16 hours attendant care a day. Under special circumstances, one can get as much as 24 hours a day. If the respiratory insufficiency is not that severe, the amount of hours needed is evaluated.

The county pays the attendants in full and that is all they do. The disabled person hires, trains, instructs, and fires. The attendants are arms and legs, and there is very little limitation for what one can have them do. No payment from the recipient is required no matter what the income might be.

This special program exists because it is believed that it takes a special relationship between the attendant and the person with respiratory insufficiency. The respiratory disabled person has to have confidence in the attendant and feel sure that an emergency situation can be handled. It is possible to travel with these attendants though a limitation in the law restricts traveling abroad.

The program is so special that less than 30 people are receiving such attendant care in Denmark. The attendant care for a person can cost as much as \$60,000 a year, but that is still cheaper than a place in a highly specialized institution. In the city of Copenhagen with 800,000 inhabitants, I am the only one living in a private home not in connection to a nursing home who is receiving this kind of attendant care.

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## TAIWAN: Rev. Robert Ronald, S.J.

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Disabled people in Taiwan look with envy on the independent movements in the United States and in Europe. I think the reason is that independent living is very dependent. It's dependent on government subsidy, on financial supports, on accessible housing, accessible transportation, and removal of architectural barriers. These are all, to some degree, problems in Asia, and particularly in Taiwan. There are no government subsidies; there's no national health insurance; or financial aid of any sort for attendant care.

It was only in 1980 that the first legislation was passed specifically for disabled persons in Taiwan, and within this legislation, independence was specifically mentioned as one of its goals. It established a registry for disabled persons. A person who carries an I.D. card establishing him as disabled is able to travel on public transportation for half-fare. There's been a tremendous increase in the number of government supported vocational training programs. It's possible for some of the disabled to get wheelchairs or artificial limbs or braces through the government supported programs.

There's a growing awareness of the needs of the disabled. The position of the disabled is improving, the number of jobs, the number of opportunities is growing, but what we lack, and what I think is so marvelous about the programs in Europe and the United States, is that the public is specifically oriented to assisting the disabled toward independence.

In Taiwan, independence is also a goal, but it's very family oriented. No disabled person would really consider himself to want independence that was free of his family. The family support system is the most important thing in the Chinese culture, and it is along lines like these that I think the independent movement will be growing in Taiwan — within the umbrella of the family to allow the person independence in the sense of being able to have opportunities to develop his interests and abilities and his aspirations. We look to the United States and Europe for the practical ways in which the public has made it possible for the disabled to achieve independence, because it has provided the accessibility and the support systems that make it possible.

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## SWEDEN: Adolf Ratzka, Ph.D.

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As the key person in the effort to import independent living philosophy to Sweden, I am tired of all the criticisms of the rugged individualism that this model supposedly implies, and that it doesn't have a place in Sweden where we take care of each other. The attacks often come from the political left which hasn't grasped the idea yet that even if the great revolution comes, we still will need services and consumer control.

The independent living movement is trying to establish strong local and national organizations which can impact policy on all levels. In Sweden, organizations of dis-

abled people are involved in planning decisions on all levels on a routine basis. On the national level, a powerful coalition influences national policy. When the government appoints a committee that is to deal with planning or social policy issues where the concerns of disabled people may be involved, the disability movement is asked to appoint representatives to this committee. In the United States, it is the President's office that would appoint the members. This is unacceptable in Sweden because representatives must be elected by this constituency in due democratic process.

In Sweden, disability organizations may often have a majority of the board consisting of disabled people, but seldom are disabled people working in the office and making the day-to-day decisions. As an example, the administrative head office of Disabled Peoples' International is located in Stockholm. None of the four people running the office is disabled. One of the explanations for this phenomenon might be that most Swedish disability organizations are organized along diagnostic lines. There is an organization for almost every disease group. This invites professionalism and may be one of the reasons why our organizations are so heavily controlled by professionals. In the U.S., on the other hand, most of the organizations have leaders with disabilities. Independent living programs associated with the National Council on Independent Living have to have a majority of disabled persons on board and staff.

The independent living movement works for services that enable disabled individuals to participate on an equal footing with the rest of society in all areas and at all levels. Sweden has had for many years a broadly supported public commitment to provide a relatively high level of such services, irrespective of income and often completely free of charge. Thus, there are extensive attendant care programs, free housing adaptation grants, and free assistive devices.

Independent living also implies that disabled individuals, the consumers, both as a group and as individuals, are in control of the provision of these services. In this area, there is still much to work for in Sweden. In attendant care, for example, most often the consumer does not have the right to decide who is to work for him or her.

The independent living movement employs the principles of peer counseling, peer support, and role modeling. In Sweden, peer counseling has not been used purposely. In fact, the term was introduced in 1983 at a seminar on independent living. The counseling that is available is provided mainly by nondisabled professionals. There is still a distinction in Sweden between professionals on the one hand and disabled people on the other hand. In the United States, a new group of disabled professionals can provide powerful role models for their clients and bring about attitudinal changes in their colleagues. In Sweden,

very rarely are persons with visible disabilities in important positions. An exception is the recent appointment of a blind person as Minister of Social Welfare in charge of disability issues. The fact that he was blind was played down by the administration and his personal experience of disability was not recognized as a merit for his office.

In conclusion, the difference between the United States and Sweden in the living conditions of disabled people and the achievements of their movements is a reflection of the sociopolitical climate of our respective countries. In Sweden, people tend to see government as a kind of insurance where, ideally, each citizen contributes according to his or her ability by paying taxes, and each receives the services he or she needs. In the United States, the doctrine of "least government is best government" is currently in vogue. While most Swedes consider it natural that the state uses taxes to provide free social services, Americans, it seems, prefer to spend their taxes on free military services, and not only for its own citizens, but to people all over the world — whether they like it or not. Why don't more disabled people in the U.S. protest and demand that their tax money be used to alleviate and not to proliferate disability? Given these basic differences, it is easier for disabled individuals in Sweden to get the consumer control needed than for disabled individuals in the United States to get the services needed.

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## THE NETHERLANDS: Geurt Heykamp

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In Holland, the Social Security System is especially for people who don't have very much money. It's quite a good system, but there is the danger of being snobbish or paternalistic towards other systems. When you think that you have a very good social security system, you're not thinking of changing it.

In Holland, people in institutions spend their days in another environment than the one in which they live. Physically disabled people and mentally retarded people were once considered as one group, and the legislation was made for only that group. Only in the last few years have people in governments started to realize that they're two specific groups with specific needs, but it takes time to change policy.

Being a member of a small movement in Holland which tries to achieve some of the things the independent living movement in the United States tries to achieve has drawn a lot of criticism from the people who think the system is fine. The criticism towards the woman's liberation movement is something to learn from. The criticism is the token that we're moving in the right direction.

# Independent Living: Attendant Care

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## Judy Heumann

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The independent living movement has identified the lack of attendant care services as one of the major obstacles to allowing persons with disabilities to live independently within their own communities. There is a growing emphasis, both within the government and the private sector, and within the disabled movement as a whole, that de-institutionalization and keeping people out of institutions is a priority. How do we successfully de-institutionalize people? How do we effectively keep people out of institutions if effective attendant services are not being provided?

The attendant care issues bring together persons of all ages, all socioeconomic backgrounds, all racial groups, and begin to allow us to work more effectively with the elderly who are now the largest users of attendant care service.

In California, 73% of the state attendant care dollar is spent on services for persons over the age of 65. Since the majority of people who use attendant care services are elderly, and since a large population in the baby boom era is moving into the elderly population, the need for an effective attendant service also educates the disabled and currently temporarily able bodied population about why this service is important not only to those of us who need the service today, but to the people who will need the service in the future.

California's program, which spends close to \$300,000,000 on attendant care and services about 100,000 people is a model social service program, which does not go through home health care agencies. In California, one has the right to hire and fire one's own workers, and, in most cases, one has the right to pay, if one is receiving more than 20 hours of personal care services, the attendant directly. In all cases, one has the right to hire and fire and train one's own attendants.

In many other countries currently with attendant services, the services are something which are considered to be the responsibility of government. Disabled individuals believe that they have a right to those services, and believe they have a right to continue to improve those services.

What federal dollars and what state dollars are currently being utilized to provide attendant care services? Who's benefitting from those services? Who's not benefitting from those services? How are those services being provided? Are they being provided primarily by home health care agencies? Are they being primarily provided in a social service model?

No one knows how many people are currently getting attendant care services, nor does anyone know how many people need attendant care services.

Who should be providing funding for attendant care

services? Should it be the federal government's responsibility completely? Should it be the state government's responsibility completely? Should it be a combination of federal and state government dollars? What role should private insurance companies play in the provision of attendant care services? Should there be a share of cost? Should there be a system in which, as one's income increased, the support would decrease, but at no point would one ever be 100% responsible for the provision of attendant care services?

What should an attendant care program provide? Should this be a program where one has the right to hire and fire and pay one's attendants? Should it be a program which is available 7 days a week, 24 hours a day? Even in areas where attendant care services are provided, in many cases, one must use a certain number of hours at a time, and often the services are only provided five days a week. Should the service only be provided to people who are at risk of being placed in an institution? Should the attendant care service provide personal care, like bowel and bladder management, etc? Should the service also provide domestic care, or domestic services like cleaning, shopping? Should the attendant care service provide transportation?

What are the implications of not having an attendant care service? What happens to the vast number of people who are in need of attendant care services, but are not getting them? Is it resulting in a poorer quality of life for disabled individuals who are not going into an institution, but are becoming institutionalized within their own home, or within their family's home? What additional disabilities are family members getting, because they are providing services that they may not be physically capable of providing? Are there people who are having to stop work in order to stay home and take care of family members who are in need of the services?

The World Institute on Disability (WID) has received funds from the National Easter Seal Research Foundation and the Mott Foundation to begin looking at attendant care issues. WID will, by June, 1985, have done a review of all 50 states to determine what public funding is currently being utilized to provide attendant care services. Medicare, Medicaid, and Social Service Block Grant Money, Title XX, are providing attendant care services. Departments of Rehabilitation in some states are providing attendant care services, and Title III of the Older American Act is providing attendant care services.

As WID surveys the 50 states, there are between 150-200 publicly modeled attendant programs. These programs are serving anywhere from nine people to 100,000 people. In some states there are as many as 12 programs, and in many cases, the programs don't even know that each other exists. Different administrative agencies are running these programs.

We should address the fact that the government and the private insurance companies believe that at least 80% of attendant care services has been provided by volunteers — husbands, wives, mothers, fathers, sisters, brothers, and next-door neighbors.

Many of the people who have been providing services for free are getting older, and as they're getting older, they're no longer able to provide the service. Who is going to replace that service? Who is going to provide that service as one becomes more disabled and maybe didn't need attendant care services in the past, but may need attendant care services in the future?

The medical industry sees this as an important service to provide, arguing that this service needs to be provided through home health care agencies. The cost of this service coming through home health care agencies is significantly inflated due to overqualified people providing this service. It is not necessary to have a registered nurse involved in attendant care services.

Many people with disabilities believe that it's their responsibility to be able to train their own attendants.

The nondisabled community needs to start discussions about attendant services and other support services, because when they're 70 years old and acquire a disability and need attendant care services as an alternative to being institutionalized, it will be too late.

The elderly who are ashamed of acknowledging their disabilities, and who believe that the acquisition of disability means that they are at death's door must see that the introduction of attendant care services is a liberating experience; that the use of attendant care services plus other support services allows people to remain in their own homes and not have to be at the risk of more costly and/or more inhumane institutionalized settings.

What role should the private insurance company be playing in the provision of attendant care? The private insurance companies should provide some form of reimbursement for attendant care services. Insurance companies now will pay more money to keep one in an institution than they will for in-home supportive services which are less expensive. Ed Roberts' insurance company will not reimburse him for his own hired attendant, whom he's paying \$6 an hour, but they will reimburse him \$15 an hour if he goes through a home health agency.

When I visit Adolf Ratzka in Sweden, I find that he's spending \$40 a month in comparison with my \$700 to \$800 a month for the same number of hours of service. I want to work and I want to contribute my tax money like everyone else, but I also feel that the government has a responsibility to give me money back so that I can be living a life like other nondisabled people in the community.

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## Harlan Hahn, Ph.D.

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Disability is being redefined from an essentially medical definition of disability, which focuses on functional impairments, and an economic definition of disability, which focuses on vocational training, to a sociopolitical definition of disability, which regards disability as a product of the interaction between the individual and the environment.

From that perspective, it's important to recognize that the problem is primarily external — we live in a disabling environment. Our efforts must be devoted to the task of altering that environment so that it becomes non-disabling, both for us and for others. Why is it that the environment in which we live is so inhospitable for people with disabilities?

Public attitudes toward people with disabilities reflect widespread evidence of antipathy, aversion, and, in some cases, hostility. It's difficult, for both disabled and nondisabled people, to come to grips with what that means, because it's easier to pretend it's not true, to pretend that the problems of prejudice and discrimination are not really a part of the challenge that we face.

The environment is shaped by public policy which is a reflection of attitudes and values that are prevalent in society. The discriminatory environment in which we exist may not be accidental or coincidental. It may be a reflection of the preferences, the predispositions, the biases, the prejudice, and the discrimination imposed upon the disabled community by the nondisabled majority.

The problem of attendant care and of environmental modifications is not primarily a problem of service delivery, but an issue of what we are entitled to as citizens of a society which must extend legal rights to all of its members.

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## Rita McGaughey

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One collaborative effort reflecting a private/public partnership is the survey which the World Institute on Disability is conducting to collect data on attendant care services. The WID study was originally funded by the Mott Foundation and later received funds from the Easter Seal Research Foundation. In supporting this study, the Easter Seal Research Foundation recognized the need it meets (by collecting data) in providing a basis for planning state and federal attendant care programs. Armed with information resulting from the WID study, advocates can make effective approaches to legislators and public agencies. Attendant programs, when developed around a sound scientific basis, can be expected to be cost-efficient as well as innovative in meeting a critical need.

This model for using data compiled through private resources to initiate programs funded by public sources has been used throughout the history of rehabilitation programs. Efforts to create the right climate for the passage of laws governing the accessibility of buildings began over twenty years before the enactment of the 1968 federal accessibility law.

In 1945, the Easter Seal Society's Board of Directors asked for an advisory committee to help decide what kinds of public education programs were going to be needed to alert the public to the kinds of obstacles and barriers that the veteran with disabilities returning from the war would face when he or she tried to get back into school systems, jobs, housing, etc. The Easter Seal Research Foundation gave a grant of just \$17,000 in 1959 to the University of Illinois to develop the specifications that were needed to get the task done.

Design specifications resulting from research at the University of Illinois continue to provide the basis for the voluntary ANSI Standard, federal and state regulations, and local building codes that govern accessibility.

In any private/public collaborative effort there is more than an innovative role for the private sector to assume. It is not enough to point to needs and suggest methods to meet them. The private sector must also assume a watchdog role to insure that the intent of legislation is indeed being carried out in public programs.

The 1968 law again provides an example. True, there was a law mandating the construction of federal buildings to meet design specifications for accessibility. However, the law lacked the "muscle" needed to make it effective. This oversight was remedied with the passage of the 1973 Rehabilitation Act which established the Architectural and Transportation Barriers Compliance Board whose function is to ensure compliance with the 1968 law.

There's an effective reservoir within the private sector continuously testing and evaluating the effectiveness of federal programs. We in the private sector have a responsibility to constantly evaluate and measure the effectiveness of those programs as well as to innovate new ones.

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### **Ron Wylie**

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Medicare is a fully federal program. The federal government pays about 55% of the Medicaid bill and the states pay the rest. Those two programs at the federal level are about \$100,000,000,000 a year, and that is one tenth of the present federal budget.

The entire budget of the Department of Health and Human Services is the third largest budget in the world, surpassed only by the national budgets of the United States and of the Soviet Union. Of that budget, 97% is in the area of Social Security and Medicare and Medicaid. Medicare alone is expending at the rate of \$8,500,000 an hour.

The significance of disability — the long-term, chronic conditions — is emerging as a major awareness. Post-polios are the second largest disability group in the country, surpassed only by strokes, with spinal cord injuries third.

The administrator of HCFA has asked me personally to initiate considerably more dialogue and outreach with groups like this, and with beneficiary groups generally. Our beneficiaries need to have considerably more insights as to what our rationales are, but even more importantly, we need, as we formulate policy, advocacy and the bearing of the correct message to the policy makers.

We haven't done what we should in terms of comprehensive services, and we need to involve the states. We need to do long-range planning.

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### **Saul Boyarsky, M.D., J.D.**

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This conference has been dealing with health and life, as a setting for scientific programs, and with concerns and human fellowship.

You all have graduated beyond being just a patient by having taken responsibility for your self-care and going

beyond it. You have progressed further spiritually. You represent a group of disabled taking care of their own, who can counsel and help all the better because you have come through it. The average physician, nurse, PT, OT, or psychologist has not had this experience, even vicariously, through a family member.

I believe that the private and public sectors of our society are wedded. It's hard to know where one ends and the other starts.

One danger in our society is that we blame government for everything we don't like and, at the same time, let it atrophy through disuse. Our government has been very well designed. The government apparatus, through historical evolution, is made to be sensitive to us individually and collectively. We have a free press which is a watchdog. Our representatives and our bureaucrats have problems of too little information, not too much information. They suffer from little participation by us in voting, lobbying, and lack of communication.

We need to educate them and the public about our special needs so that they help where possible. I am glad to see the government involved in this conference directly since it facilitates such valuable and vital communication.

There's prejudice against "lobbying." Lobbying is not just a special interest thing you do. It can be, and it should be, a privilege and a duty of each citizen to educate the legislator or the regulator. The real problem is ignorance, the lack of awareness and lack of concern in the general population which the legislators have to live with. They cannot act like enlightened legislators without us.

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### **Adolf Ratzka, Ph.D.**

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The terms "attendant" and "care" carry institutional connotations and project the image of passivity and dependence. I use the term "personal assistants" because disabled individuals need to view themselves as self-directed, independent people who are capable of managing their own lives. The way personal assistance is organized can either thwart consumers' potential for growth and self-direction or enable them to live as active and productive members of their community.

Social policy is most often not made by the people whose lives are affected by it. If consumer groups succeed in lobbying for a reform, they rarely have the possibility of getting involved in the actual design of policy instruments. Because of an alleged lack of administrative experience or formal qualifications, it is common to leave this work up to administrators, social workers, medical doctors, and lawyers. There are a growing number of professionally trained people with disabilities whose expertise as consumers is underestimated. Since consumers have the most intimate experience of how personal assistance influences their lives, they have to formulate their needs and translate them into design criteria. If the design of personal assistance programs is left to government agencies, the system will conform to their needs but not necessarily to those of disabled individuals. Consumers must be decisively involved in designing the program.

Service delivery must encompass all needs. In order

to live full and active lives, disabled individuals need personal assistance with a variety of activities, such as personal hygiene, dressing, household chores, driving, shopping, sign language interpreting, in a variety of situations. To break up these needs into several distinct programs for certain activities and certain situations, as practiced in some countries, can entail several funding sources and separate service delivery systems, each with its own eligibility requirements, administrative routines, and staff. As the number of different agencies involved increases, so does the consumer's vulnerability, since problems can arise in any link of the chain. The most far-reaching consequence is the sense of alienation and powerlessness which the division of responsibility for the programs breeds in consumers.

General solutions cannot satisfy individual needs. Government agencies, if left alone, tend to develop a single solution that is to satisfy all needs, because from an administrative point of view a single service delivery system is preferred. Yet disabled people are unique individuals with individual physical needs, personal resources, and life circumstances. For each individual, needs will vary over time as family situation, occupational status, interests, and health change. Personal assistance systems must adapt to needs, not the other way round. Choice is the key to independent living.

Programs must encourage consumers' productivity and gainful employment. In many countries personal assistance programs are means tested which leads to undesirable consequences. For one, coverage of the costs of assistance may be seen by the general population and consumers as a welfare payment which can have stigmatizing effects. Also, means tested eligibility can act as an effective deterrent for gainful employment.

Consumers do not have the same possibilities of demanding competent, punctual, and courteous work from volunteers as from assistants who are paid competitive wages. One is likely to have more personal power and more independence when you function as an employer instead of an object of charity.

Funding must be as centralized as possible at the federal level. Single source funding at the federal level eliminates costly bureaucracy and regional inequalities that otherwise seriously impede disabled people's geographical and social mobility. Only at the national income tax level can all benefits from a personal assistance policy be internalized. Where personal assistance is financed by local governments and institutional care facilities by regional governments, local governments do not reap the financial benefits of de-institutionalization made possible by personal assistance. Personal assistance programs enable many citizens with disabilities to become gainfully employed thereby contributing to national income tax revenues. This is also true for family members who otherwise would often be forced to informally provide these services and whom such programs enable to pursue employment outside the home. The ideal single funding source is a federal tax-funded personal assistance insurance without means test.

Control over service delivery must be as decentralized as possible at the consumer level. Consumers are the best experts on their needs and must be able to decide

what activities they need assistance with and how many different persons are to work. They have to have the right to recruit, hire, schedule, pay, and — if necessary — fire their staff. To rely on workers from an agency can involve high turnover which is inefficient.

Severely disabled individuals have specialized needs that differ from person to person. New workers have to be instructed and trained by the consumer in new work routines which takes time and effort. Having to depend on strangers can be humiliating, since the work constitutes a close social relationship and consists of very personal and intimate activities. The assumption that any assistant can work for any person amounts to a denial of an individual's uniqueness as a human being.

Among the benefits of assuming responsibility for one's service system are the dignity of being able to make mistakes, the rewards of learning from them, and the acquisition of useful management skills. These experiences and social skills are useful for other areas of one's life, such as employment, and lead to increased self-confidence.

Administrators and trade unions often propagate more professionalism in the hope of upgrading assistants' status and improving the service. The criteria for professionalism (commonly health care related formal qualifications and training) represent an obstacle to consumers' realization of their potential for self-direction, if the attitude is conveyed that consumers are patients who need to be taken care of. Consumers who want to improve the quality of the service, and thereby the quality of their lives have to take more initiative and work with their assistants as a team where consumers instruct and direct. In order to support consumers in this role, independent living skills and peer counseling classes should be offered by organizations of disabled people.

Institutions do not have to consist of brick and mortar. If consumers cannot choose who is to work, if they accept service without alternatives, if they do not meet assistants as individuals on a one-to-one basis but deal with a hierarchically ordered organization, then they are facing an institution.

It is typical for institutions that as orders or rules are passed down from one echelon to the next, their interpretation automatically becomes narrower as employees voluntarily limit their own margins for decision making in order to avoid making a mistake. The individual consumer is powerless at the bottom of the pyramid. Institutional vestiges in service delivery must be identified before programs can be designed which truly support disabled people's emancipation.

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### **Harlan Hahn, Ph.D.**

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We sometimes fail to understand that a smooth trek for some people, particularly the disabled in this environment, is a Byzantine obstacle course for many persons with disabilities. We need to demonstrate that our legal rights should not be shaped or restricted by an environment which was designed without regard to our needs and interests. If we require attendant services or personal assistance, it is part of our responsibility to alter an environment in that manner. We can have an environment like

that, provided there are enough of us willing to identify ourselves as people with disabilities for political purposes, and to organize and mobilize to achieve the kind of environment in which attendant services will be granted as a right rather than a privilege.

A national health program is needed for people with disabilities. Anything short imperils our health. We should give serious consideration to a proposal currently being debated in Great Britain — a proposal for a non-means

tested disability allowance. That is, a flat payment to all people with disabilities, regardless of how many resources they have, in recognition of the fact that a disabling environment imposes costs upon us that must be ameliorated. The costs are not really the product of our disabilities, but a product of an environment which makes it difficult for us to function and to be equal in society. Those are proposals that I'd like to put on the agenda: a national health program and a disability allowance.





# Gazette International Networking Institute (G.I.N.I.)

Reaching, informing, and dignifying people with disabilities throughout the world.

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## Origin

*Rehabilitation Gazette*, an international journal for independent living by people with disabilities, was started by Gini Laurie in 1958 for polio survivors in iron lungs to share their information and experiences.

The *Gazette* grew from a local newsletter to a renowned international journal and evolved to include other physical disabilities and the aging of all disabled persons.

In 1983, The *Gazette* celebrated its 25th year as a journal and information service, and was reorganized to expand its services. The new organization was named Gazette International Networking Institute (G.I.N.I.).

G.I.N.I. is incorporated as a non-profit [501 (c) (3)] organization. Donations are tax-deductible.

## Publications

Published since 1958, *Rehabilitation Gazette* embodies and reflects the imaginative, practical, down-to-earth life experiences of its disabled readers.

It is a form of peer counseling and therapy by mail, an invaluable source of ideas, inventions, and adaptations that have been tried and found useful by others. Personal experiences in the *Gazette's* articles motivate other readers to live full and independent lives.

The *Gazette* is an invaluable tool for creative rehabilitation, providing health care professionals with additional insight into the interests and needs of people with disabilities. Readers include doctors, nurses, therapists, social workers, rehabilitation counselors, government officials, educators, and the relatives and friends of persons with disabilities.

The *Gazette* reaches 30,000–50,000 readers in 87 countries with translations in five languages. It is read by people who are disabled with ALS, amputation, arthritis, cerebral palsy, head injury, multiple sclerosis, muscular dystrophy, polio, spinal cord injury, and stroke.

In 1986, G.I.N.I. began publishing two issues of the *Gazette* per year and offered membership in the G.I.N.I. organization. Membership benefits include a subscription to *Rehabilitation Gazette*, G.I.N.I.'s information service and library, and discounts on G.I.N.I. conferences and membership events.

Other G.I.N.I. publications include the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* and the proceedings of G.I.N.I.'s polio and independent living conferences. Order forms are available from G.I.N.I.

## Polio Network

G.I.N.I. has maintained a worldwide polio network since 1958. Consequently, when an increasing number of polio survivors began to report new symptoms of pain, fatigue, weakness, and breathing difficulties, G.I.N.I. took the lead in organizing the first coordinated look at the problems with its 1981 polio conference.

G.I.N.I.'s subsequent biennial polio conferences continue to educate physicians, promote research, and provide information and psychological support to polio survivors.

In 1985, G.I.N.I. formally established the International Polio Network (I.P.N.) to link polio survivors and to encourage the formation of post-polio support groups.

G.I.N.I. publishes the *Polio Network News*, a quarterly bulletin for I.P.N. members and coordinates and maintains the national and international directory of post-polio support groups, clinics, and physicians.

I.P.N. membership forms are available to all interested persons from G.I.N.I.

## Ventilator Users Network

Polio survivors who started using home mechanical ventilation in the 1950s formed the nucleus of G.I.N.I.'s International Ventilator Users Network (I.V.U.N.).

I.V.U.N. links ventilator users with each other and with medical personnel interested in home mechanical ventilation. These ventilator users include infants, children, and adults disabled by neuromuscular diseases or injuries affecting the respiratory system.

I.V.U.N.'s members receive a bi-annual newsletter featuring ventilator equipment and adaptations, glossopharyngeal breathing techniques, psychosocial aspects of long-term ventilator use, sleep disorders, organizations concerned with ventilator users, travel, etc.

Membership forms are available from G.I.N.I.

## Information Service and Networking

G.I.N.I. is a primary source of specialized information on do-it-yourself equipment, independent living, polio, spinal cord injury, and ventilators.

The library, with materials amassed over 35 years, is a special collection of books, periodicals, monographs and reports, pamphlets, clippings, and case histories.

Using the library's unique resources, G.I.N.I. answers questions on disability-related subjects, such as architectural and attitudinal barriers, civil rights, housing adaptations, wheelchairs, vans and lifts, etc. Questions about coping with disability are answered by referrals among G.I.N.I.'s international people network.

The information service is available only to G.I.N.I. members.

## Independent Living

Gini Laurie is well known as the historian of the independent living movement. She has watched and encouraged the growth of the independent living centers since the early 1970s.

The lives of disabled individuals as role models are chronicled in the pages of the *Gazette* and parallel the evolution of the independent living movement.

G.I.N.I. provides information on all aspects of independent living including attendants, education, employment, equipment, family life, sex, sports, and travel.

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