

#### **IV. PUBLIC AND FAMILY EDUCATION**

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**Roberta Barber, B.C. Ministry of Social Services:**

I am Coordinator of the Health Services Branch of the Income Assistance Division, British Columbia Ministry of Social Services. Our main function is to provide medical services and goods to income-assistance clients or other individuals in need. It is mandated under the same Act and Regulations as "Income Assistance" and ours is an income assistance benefit. Depending on whether you are on income assistance or just someone in need of our help, some of the services we provide are medical, medical transportation, Pharmacare benefits, emergency dental and other limited dental services, limited optical services, medical goods and supplies, hearing aids, and therapy.

The therapies in particular are physiotherapy, massage, and chiropractic. Of interest to this particular group would be assistance with medical goods and supplies. Some that we supply are bandages and dressings, hospital beds and specialized beds, braces, burn treatment garments, canes, crutches, catheters, commode chairs, mobility needs, respiratory aids, walkers, wheelchairs and some shower chairs. These services are provided through our District offices and are administered directly through them. We act as consultants to the Ministry offices. Every service we provide is income tested. Some things we will not provide are communication equipment, vitamins, over-the-counter drugs, and some medications.

**Bert Hillmer, Employment and Immigration Canada:**

Since 1974 I have been part of the Canada Employment picture, a general counsellor part of the time, but for the past few years I have been doing "special needs" counselling. Most of our offices throughout Canada have "special needs counsellors" who deal only with special needs people. I'd like to give you an overview of our Department, and certain perspectives.

My job entails dealing with the labor market picture including free trading. Our mandate states that we are to augment the skills of Canada's human resources and the labor market. For people with a disability or a special need, I am going

to zero in on special programs for them. We help people to find jobs. We don't do the work of looking for the jobs, but we do help them find their way in that area if some one has become disabled through accident or disease such as we are talking about today. My mandate is to sit down and do some counselling. One of the priorities is to determine what kind of career the person should get into. It may be necessary to make a total change, so we have access to vocational psychologists, experts outside of our own department, who are in private practice and who do really in-depth vocational testing, including aptitude testing, vocational interest testing, as well as physical testing. Locally, we have use of a hospital in Vancouver for physical endurance tests, and we also have access to the services of the Workers' Compensation Board.

When it comes to retraining, there are a number of programs set up by the government which allow us to purchase, or (with an employer) negotiate for, a training-on-the-job program. For somebody with a disability it means we will share the costs of salary up to 60%, although generally we work on a 50% basis. In addition to that, we also provide assistance to cover training costs. For those with a disability we will provide up to \$10,000 per client to make the adjustment to the workplace. If the job requires wheelchair accessibility, we put in, or help to put in, a ramp, adjust the size of a washroom door, or whatever is needed. Basically our retraining program involves doing this kind of thing. It can be a combination of on-the-job training and classroom training, and we do share the costs of that. There is also formal classroom training for the whole population.

Somebody in Ottawa decided that certain occupations are more in demand than others and they set up a list. There is a full range of training opportunities that we cannot be involved in. With certain exceptions, by law we can only purchase a training course that lasts no more than 52 weeks, which basically means trades training, some computer training and some nursing-aid training, that kind of thing. One of the advantages we have in this specialty field is that we work very closely with the provincial government, not with the Ministry of Health but with the Vocational Rehabilitation Service. We put our heads together and come up with a plan for our clients. They can purchase long-range training which I cannot.

**Mike Carleton, Premier's Council for the Disabled:**

I am the Executive Director of the Premier's Council for the Disabled, British Columbia. Prior to this appointment I was involved with the Workers' Compensation Board for 17 years. Working with the Council is an opportunity to get involved in policy development. It is exciting, and I think it offers opportunities for people with disabilities to liaise with government and to have an impact on policy.

Our mission is to act as a catalyst to influence social policy related to the quality of life for persons with disabilities, and it is a broad mission. This is a huge undertaking, as we all know. The issues of disabilities are complex, many-faceted, and the Council has finite resources. So we must concentrate our resources on those issues where we can make a difference. We are looking at cross-disability issues which affect the larger numbers of people, rather than those which certainly have an impact for a particular disability group, but do not affect larger numbers of consumers or disabled people. For example, appropriate affordable housing is a major concern of people with head injuries, those with mental illness, and many people with physical disabilities. If this particular issue is one in which we are able to bring about some substantive changes in terms of policy and availability of that type of housing, then we will ensure that a wide range of consumers are benefiting from our work.

In terms of the types of things we are working on, we are concerned with equitable access to services provided by government. We also are developing a computerized directory of services so that people throughout the province will know where to go for services. We are also interested in public education and awareness, a huge task which is to be done in concert with other organizations. We are interested in the prevention of disabilities, which is also a matter of public education. We are currently developing an action plan for the next 5 years. We are also looking at the many issues raised by various advocate groups and by consumers themselves.

As a Council, we want to work closely with the people we represent, so when I say we are developing goals, we are developing those goals on the basis of the educational process, the input that was gathered when the Council was formed by the Steering Committee for the Premier's Council for the Disabled. Once we can put these goals into an action plan, we are going to be asking for further input from a wide range of consumers just to make certain we are on the right

track, that we are indeed working for the people we represent and are doing it based on the most appropriate order of events.

As a Council we are concerned with developing a continuum of services that would not be fragmented. Our position is that people with disabilities are first and foremost citizens; and as citizens have full equality with all other citizens. This concept is simple but powerful. If we can fully develop it within government at a policy-making level, it will mean that future public policy development will be based on the concept of equality and the rights of ALL citizens to fully participate in society. In order for that to happen, the supports have to be there, the services have to be there, and the equity of access to services has to be there.

In summary, the Council is just getting started in terms of the development of our action plan. We should be releasing this information to people and organizations throughout the province, letting people know exactly where we are going. We are looking forward to receiving input from people and we are going to try to make things happen!

**Lloyd Deering, Sun Life Insurance, Edmonton:**

I am a Rehabilitation Counsellor and have been in the field of rehabilitation for fifteen years. Part of the reason I am here is because people in the Post Polio Awareness and Support Society have brought me their questions and concerns about long-term disability in rehabilitation. So, first of all, I shall address the question of the entitlement to benefits and the claims issues, inform you of what Sun Life does, then look at how most insurance companies deal with vocational rehabilitation of people with disabilities, particularly focusing on people with post polio.

Apparently there have been people who have applied for long term disability benefits through their group insurance plans and those benefits either have not been approved, or approval has been achieved with much difficulty. I have worked with two claimants in southern British Columbia who made claims for the long term disability and Sun Life has approved them. They brought up the question "what is Sun Life's policy regarding acceptance or recognition of people who have had polio, and who are suffering post-polio problems, as far as their entitlements to long-term disability?" I pursued the answer to their question up through our administrative channels and the response I received was

that, in fact, Sun Life had no policy regarding acceptance of post polio, nor do we have a policy with regard to ANY specific disability. The criteria Sun Life and many Insurance companies use is strictly a question of whether the disability prevents the post polio persons from carrying out the duties of either their regular position or any other duties for which they may be reasonably qualified.

Most long-term disability policies have two phases, the initial phase is usually for two months, when you are entitled to the monthly benefit and monthly allowance as long as there is medical evidence concerning an inability to carry out the duties of your own occupation, whatever that may be and for whichever employer you work. If your disability prevents you from carrying out that occupation, you will be entitled to benefits as long as there is medical evidence to that effect. Usually after a period of approximately 24 months (most policies seem to have that split) you would continue to be entitled to benefits, if there is medical evidence that you are totally disabled from any occupation for which you are reasonably qualified. For instance, of the two ladies I mentioned before, one was very severely disabled, not only quite unable to carry out her regular occupational duties but in fact her disabilities would preclude any form of employment, and indeed she had extreme difficulty in even getting around in her own home.

In the other instance, Sun Life rehabilitation plan supplements her part-time earnings beyond the 24-month level, a period at the end of which the benefits would normally stop. Even that solution took a lot of my time and effort to get it accepted and approved. I discussed this with representatives of several other Insurance companies, and it became apparent they all take a similar approach, namely, they don't recognize any disability as such but base their decision on the question: "Does the disability medically prevent that person from engaging in employment?"

If you have difficulty in establishing a claim for long-term disability, I think the avenue to pursue is with your doctor who can provide medical evidence on your behalf. To address the question of the impact of the disability on the employability of the claimant, would be the prime avenue I would encourage people to pursue for most claims. Of course, once a claim is established, we then can become involved with rehabilitation. Most companies have Vocational Rehabilitation Counsellors scattered throughout the country to work with claimants receiving disability to see if we can assist those persons to return to employment suitable to them. Many people have residual abilities and a real

desire to keep working, and we have a program where if a person is interested in part-time work and the employer is willing to continue the employment on that basis, the person can receive part-time earnings and benefits from the insurance carrier. If retraining is required, we frequently work with Employment Canada and other services to look at such issues as vocational testing using the "Choices Program", a positive way to determine aptitudes and interests and how they may be utilized in employment within that person's residual abilities, perhaps to include funding for the necessary training. And, in British Columbia, community colleges have accessible facilities and special needs counsellors to coordinate the training programs. When the disability arises, most insurers take a positive approach towards guiding and helping the person in the rehabilitation process when that person cannot continue to perform their employment duties. But Sun Life, as do other insurers, does have Vocational Rehabilitation Counsellors like myself who are very interested in helping disability claimants.

**Karen Kersey, Reporter for the "Surrey Leader":**

It was through Community Connection that I ran across a program on post polio syndrome and that was the first I had ever heard of it. I interviewed a woman who told me about when she was training to be a nurse in Saskatoon. In the last months of her training she was stricken with polio, and then worked as a general duty nurse from her wheelchair. I thought she was extremely courageous. Stories like hers tend to grab a reporter. If you can share your story (we call this a "hook" for a story), and if you can find a reporter or journalist who is sensitive and who is in the field of feature article writing, you will find they will treat your story in a very sensitive manner and will draw out the story without it becoming overly sloppy or too cold and harsh. One of the important things, when you do approach the media for some coverage, is feeling that you want to share your experiences.

When going to a radio or TV interview remember the five "W's", Who, What, When, Where, and Why. If you are writing a press release, cover all the "W's" and add "How" as well. Who you are; What you are trying to do; When and Where you are going to do it; Why you are doing it; and How it will be done. Follow up with a phone call. Identify yourself. Offer more than is covered in your press release and be creative with it. If an organization gives your group a donation, tell Where and How the \$5,000 or the \$500 will be used, so that the readers or viewers can see the whole picture. Such poignant word pictures

evolving from your personal situations are important to the person to whom you are addressing your story. Involve community newspapers and cablevision stations. Phone your cablevision company, and say: "Can you do a half hour program on this particular subject. We've got this woman, we've got this man, we've got this doctor, we've got that expert, we've got people that are interested in giving a nice rounded program." Nine times out of ten they'll say "sure, let's set a date and talk about it."



## **V. MINISTRY OF HEALTH SERVICES**

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### **Lenora Angel, Public Health Nursing:**

I am a nursing administrator from Prince George. I will be speaking about community and family health services and most specifically about public health nursing services. My two colleagues represent continuing care and community physiotherapy and they will discuss those services.

The focus of Public Health Nursing is basically the promotion of health and the prevention of illness. We promote healthy behaviours in communities and among individuals and families. Our aim is to promote wellness and to help people maintain as healthy a lifestyle as possible. We also promote community support systems. I believe that is one of the areas where we can be of assistance in your home communities - in terms of networking and in the service we can provide.

We generally work in two areas of prevention. Primary prevention, in terms of Polio, is immunization. That area comes under the communicable disease program. Also, we facilitate secondary prevention through education and the dissemination of information into communities. In this way we can act as a link for survivors and families to the Post Polio Awareness and Support Society by providing names and information. We often get people calling the Health Unit who are not aware of the resources within the community and we will direct them to whoever is able to meet their needs.

The process by which we deliver our services is not as visible as those services provided by continuing care. Basically, our role is that of facilitator. We don't provide hands-on-help to our clientele. We do not have the expertise to advise on the type of aids you might need or the type of therapy necessary. However, we can tell you about what services are available, where they are available and what your options are. We can assist individuals in obtaining information on services available in other locations nearby or in other areas of the province, if this is necessary. We assist in networking, by making people aware of the services available in the community and also by assisting in communicating what services are desired by that community. We also provide some counselling services.

The public health nurses are very adept at providing lifestyle education services, nutritional and other lifestyle concerns such as stress reduction. If we don't have the expertise, we provide resources or make referrals to other counselling services; and let you know what your options might be. We promote community and individual responsibility for health and we can assist in educating the community about Post Polio Syndrome. We can help with finding solutions to problems that exist for you within your community. I think by working together in developing community resources we can support independent functioning, whether it is by helping an individual find the appropriate resource or by educating the community as a whole, regarding such matters as wheelchair accessibility. These are the types of areas in which the public health nurse functions. We are facilitators, consultants and providers of information.

**Peggy Ball, Continuing Care:**

My purpose today is two-fold: First, I want to tell you a little bit about the services that the Ministry provides, and secondly, I want to take your concerns back to the Ministry so they can address them. I want to talk about the continuing care division as a whole. We have a range of services which we provide through three major programs. They are community physiotherapy, home nursing care and the long term care program. The first program I will discuss is the home nursing care program which provides nursing services to individuals in their home for either acute, chronic or terminal illness.

**Home Nursing Care.** The services are provided most times on discharge from hospital or as an alternative to admission to an acute care hospital. Wherever possible, the client or family are encouraged to handle or learn to provide the treatments required independently with occasional supervision and demonstration from our home care nurses. We encourage independence as much as possible. In the fiscal year 1988-89 the program had approximately 35,000 clients across the province. Approximately 21,000 of them were over the age of 65 and approximately 3,000 over the age of 85. Home nursing care services approximately 7,600 clients each day.

To be more specific, home nursing care is provided in your home with direction from your physician. We have seven days a week service, with limited service on weekends. We give service on a non-emergency type basis and we're open

from approximately 8:00 a.m. to 4:30 p.m. with evening visits as required. The program pays for supplies for clients for two weeks at admission and then after that the client is responsible for their own supplies. All ages are eligible for admission to the home nursing care program. A request for service may originate from any source but most referrals are initiated from physicians, either at discharge from an acute care hospital or from their community based offices. A physician must be involved in the care that we provide in the home and specific orders are required for treatment and medication.

The benefits to having a home nursing care program are that it promotes the maintenance of family relationships by allowing people to remain in the home when they are requiring care. It allows for personal and family involvement in the planning and provision of care which is important in a person's recovery. It offers choices to those who require palliative care in that they can remain at home until death. It enhances recovery from illness and allows for earlier return to normal activities and is considered to be cost effective.

Home care nurses usually have at least two years of medical/surgical background. They are able to provide professional assessment of your needs, identify problems, and assist with planning your care. They are familiar with community resources and are able to coordinate services for individuals and create liaisons between agencies. They are all members of the Registered Nursing Association of B.C. These nurses are employed by the Ministry of Health in the Continuing Care Division.

Specific types of care home care nurses might provide would be those services necessary for diabetics involving insulin administration and preloading of syringes. They are heavily involved in palliative care and work with hospice groups. The nurses do pain control and administer medication. We provide emotional support to the client and family. We do ostomy care and teach and promote independence in that area. We do application of appliances, wound care, sterile dressings, heat applications and irrigations. We do cardiac management so we may get a referral following myocardial infarction. We monitor vital signs, discuss risk factors and help in cardiac management. We also do medication management.

We do get called in periodically to go into homes to assess physical environments and people's abilities to perform their activities of daily living. We see whether they're able to bath independently or how they're managing in the home and if it seems to be a bit above our level of expertise we'll call in

another member of our program. The physiotherapy group would come in to measure for different aids that you might require. We operate very much as a team with the three programs. Another aspect we may be called in on is regarding oxygen which Pharmacare has taken over, but our home care nurses still do the initial assessment on a doctor's referral.

**Long Term Care.** The long term care program addresses long term non-acute health related problems and helps to maintain optimal levels of independent functioning of individuals. Long term staff assess the clients' needs and develop care plans to help meet these needs, whether it is in the form of homemaker support or nursing care or whatever it requires to maintain the client in the home. Services provided through the long term care program include assessment of health status, functional abilities, and service needs.

We do care planning for community living and promote independence. We refer to other community resources as needed. We purchase service on behalf of clients, an example would be homemaking. We also do weight lifting for residential care when necessary and appropriate. We coordinate other health services within our program of home nursing care and community physiotherapy. We also refer to community and family health.

To be eligible for long term care benefits, a person must be a Canadian citizen or permanent resident and have resided in B.C. for twelve months; have a health related handicap or disability of a long term nature that necessitates assistance with activities of daily living. The client must also be 19 years of age or older. A referral to the long term care program can be made by anyone; but before any services are initiated, a long term care assessor, or case manager would go to your home for an interview to determine what your needs are.

The costs associated with the homemaking service provided in the home are directly related to income, and are determined by a financial assessment which is part of the initial assessment. In the majority of instances the cost of homemaking is a small one, although I understand in some cases people are paying more than they anticipated they would have to.

In the fiscal year 1988-89 approximately 8,000 people over the age of 85 received home making services which allowed them to remain independently in their homes. Homemaker services had an average of 36,213 clients every day. The total number of clients using this service in 1987-88 approached 50,000. Seniors account for the majority of clients. In 1988-89 they feel over 42,000

seniors over the age of 65 are receiving this service. The sex breakdown for homemaking service is 70% female to 30% male.

Homemakers perform a number of functions in the home. They will assist you with bathing or personal care, shampooing etc. They also help you to maintain the home by doing the vacuuming, washing floors and doing laundry every couple of weeks. In exceptional circumstances they will also do some meal preparation, banking once a month or shopping.

### **Sue Ward, Community Physiotherapy:**

I am a physiotherapist based in Nanaimo on Vancouver Island. First I'm just going to run through the community physiotherapy service and what we can provide for you. Then I will speak to you about what I've learned about treating Post Polio syndrome from three patients in my area and from my preparation for this conference.

There are 19 community physiotherapists based in health units throughout the province. We find the majority of physiotherapists and occupational therapists working in the municipalities of Vancouver, Burnaby, Richmond, North Vancouver, and Victoria. We provide consultation and an assessment service. We have to do this rather than a direct hands-on treatment service to everyone because of the vast areas we cover. We use a problem solving approach to get the highest possible degree of function and independence in the home. We have a much broader expertise than just exercise or massage for increasing your function in the home. We may have to adapt your environment by putting a raise on the toilet seat or grab bars in the bathroom. Perhaps you need a floor to ceiling pole by your chair or your bed. You may need to have your favourite reclining chair put on a platform. Perhaps, we can work with energy conservation by adapting a kitchen layout so one can function with less effort. This is a broader spectrum than just exercises.

We encourage self responsibility for health through advice and education. We have educational sessions and health promotions. In some cases in outlying areas where there are no other resources we perform some treatments. An example of a group educational session we might do would be with the stroke clubs. Other examples are programs for Parkinson's groups, multiple sclerosis groups, disabled riding groups, pre-natal classes, disabled swim classes, etc.

We do not provide equipment per se, but we are very instrumental in helping you access equipment. We can help with the choice of appropriate equipment and also with organizing financing through social services, veteran's affairs or Kinsmen. We have a small selection of equipment that we can loan out to clients for a trial time so they can determine what is appropriate for them.

Treatment for Post Polio Syndrome is divided into two sections. Firstly, there is an exercise program and secondly there are techniques for decreasing fatigue. This comes under the heading of energy conservation, by balancing periods of activity with periods of rest. Regarding exercises, Dr. Ruben Feldman from the Rehabilitation Department at the University of Alberta has developed a program. The criteria for admission to this program are having had polio 20 - 40 years ago and having a normal recovery with new symptoms now being experienced. After acute polio and a normal recovery those muscle groups are now showing signs of either fatigue or pain.

When the physiotherapist receives the referral, there will be two groups of muscles listed. One group of muscles which have been tested electronically with EMG will show signs of Post Polio syndrome while the other group will show that they are healthy muscles but are weakened due to inactivity. The main focus of the program is to stop the exercising before the muscles fatigue. If one goes past this point, the muscles will suffer from over use and there will be a deterioration of muscle strength. The physiotherapist and the patient must become very adept at recognizing the signs of fatigue.

There are various ways to determine when this is happening. One is a feeling of tiredness and the other is through the deterioration in the quality of the muscle movement. Any of these symptoms must be avoided. Physiotherapists speak of muscle strength in grades of 0 - 5. At 0 there is no movement, not even a flicker. At 1 you will not see any movement, you can see the muscle trying to work which would be by seeing a tendon start to tighten for example. 2 is when the muscle can work with gravity eliminated. 3 is when the muscle can work against gravity. 4 is when the muscle is able to function against gravity and also against a resistance such as a weight for example. 5 would be a normal measurement. The muscles with only a strength of 1 - 3 would really only be able to maintain their strength. You might achieve efficient contraction but this would only be a maintenance program. With muscles in the range of 3 - 5 we might be able to increase strength. To do this we use the techniques of biofeedback and slings. The slings have canvas straps with ropes attached. Many physiotherapy departments use these to eliminate gravity.

One wants to re-educate the muscle to perform without compensatory movements. This is even more important with the walking muscles to achieve a proper gait. Biofeedback is a similar mechanism where it stimulates the muscle to perform the correct movement. Another method is through watching the muscle perform which sends valuable feedback to the brain. It also works in the same manner with the physiotherapist telling you what to do. This is a stimulus to the brain to make the nerves send the right message to the muscle. One would tend to stay with the sling system until the muscles have been built up to grade 4 or more. If this method is stopped too early one will re-develop the compensatory movements or bad habits. From this one would go on to normal anti-gravity exercises and then onto anti-gravity exercises with a weight or resistance.

There is a specific way to add the weights and to assess how much weight to use. You determine the maximum amount you can use to do five repetitions, without getting tired. In other words say I put two pounds in my hand and I do this five times and I'm fine. Then on the sixth time it's obvious either I can't get it right up or I'm compensating. Therefore two pounds would be the maximum. Then starting the program you would begin with 50% of this maximum which would be one pound. You would perform the exercise five times. The number of times the exercise would be performed would be increased until you reached a maximum of thirty. Then you would advance to using 75% of the original weight, performing the exercise only five times to begin with and then increase this until the maximum of thirty was achieved. Finally you would advance to the maximum weight of two pounds and increase your repetitions as with the lesser weights. This is a structured way of building up the muscles with the rational of avoiding fatigue.

Another interesting aspect is that the muscles affected by polio should only be exercised on alternative days. Muscles which are just generally weak but otherwise healthy can be exercised daily. After an exercise session it is very important to rest for 1/2 to 1 hour. The rest period is very important and this is a difficulty when attending a hospital or clinic facility. Once the patient can perform these exercises at home it is much better. Our physiotherapists can help you simulate the equipment in the hospital for use at home.

A word about mobility aids now. There are many mobility aids available such as canes, walkers, crutches, chairs, etc. Many people have a great resistance to using such an aid or switching to another type. A person can actually gain



independence through the use of an aid as it will decrease the fatigue level. Regarding swimming as an exercise, I'd be a little reserved as it is difficult to differentiate between over-using the post polio muscles and one could get overtired. However, exercises in water, especially specific exercises are great. Basically, the important thing to remember is to respect fatigue. This is a treatment and not a cure so the program has to be ongoing even if it is only a maintenance program. One has to take responsibility oneself. In planning an activity such as golf for example, plan to golf only 9 holes perhaps instead of causing over-use and fatigue by pushing to do 18 holes. With an energy conservation plan organize the activity, whether it is writing letters or baking or whatever, so that you don't have to keep getting up for supplies.

## **VI. TREATMENT**

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### **Barbara Reynolds, Physiotherapist:**

The treatment of post-polio syndrome consists of two components - the first I'll outline is a "non-fatiguing regime of exercises"; the second is "energy conservation" which Nanw Roger will address.

How do you exercise the muscles which appear to be already overworked and over-fatigued? When we began our program two years ago there was minimal information on exercise protocols and some literature was stating "No Exercise!". We literally experimented with a group of very eager, courageous people (some of whom are here in the audience today). It is nice to see you. I was about to give them a program of non-fatiguing exercises - the name implies that you will not be tired, you will relax, you will not sweat, and you will not feel as if you have worked out. Remember the saying "No Pain, No Gain"? Well, that is no longer in vogue. Thirty years ago, physiotherapists treated patients with polio like athletes. Well, as a profession, we have come a long way. No longer is hard and systematic exercise the key to functional improvement. This is probably the most difficult concept for those of you with "post-polio syndrome" to come to terms with and to understand.

The initial assessment in our facility consists of a history and functional status assessment of the patient, with special attention to any new problems being experienced. For this we use the OMOD survey, of which you are aware. It contains a list of activities like bathing, climbing stairs, lifting, things like that, and what we do is ask patients to write down on this sheet the date or year when they first started finding problems such as getting out of the bath. They also rate each activity on a scale of difficulty or how much of a problem it is for you, rating it as "mild, moderate, or severe".

What this does, is give you an idea of just how slow the progression is, and in many people's minds I think this alleviates the concern. If you said "I realized in 1982 having a bath was difficult because I couldn't get out of the bathtub, and then in 1987 climbing stairs became a serious problem", to me that shows that both problems are related to decreased strength in your lower extremities. But there is a long gap before one relates to the other. It just shows, as was

mentioned yesterday, that it progresses very slowly. It doesn't mean because you can no longer climb stairs today, that tomorrow you are going to be in a scooter or wheelchair. That is not the case at all.

This is followed by a manual muscle test, in which I get an overview of the strength of the muscle groups. With this information, patients are sent to be tested on the Kin Com, a machine which gives us an accurate, computerized printout of the maximum muscle strength of specific muscles. Some of the patients who went through the programme initially, were over-tested, and they suffered for it. But we have learned from that. Our goal, in an exercise programme, is to improve function and endurance. Patients exercise on alternate days, then comment whether they experienced fatigue, pain, and/or muscle twitching, and whether they had lifestyle changes which affected how they felt. In other words they could be exercising for Day 1, and rest on Day 2, and they just write down "feel fine." On Day 3 they exercise, and then on Day 4 report "I feel rotten", (maybe because they were partying all night).

I am now going to give you some definitions. Weight - as we use it - is the resistance which specific muscle groups will work against, and the weights chosen are 25% of that determined by your Kin Com test results. We started off by using Dr. Feldman's protocol of using 50%. This, we soon found with the first couple of patients, was far too heavy and people were fatiguing much too fast. So we cut that down to 25%. Interestingly enough, yesterday we learned that Dr. Yarnell's program of resistance was 20%, so we are in the same ballpark, even though our level was determined strictly by trial and error. Each repetition is the number of times you would repeat an exercise, and a set is the total number of repetitions completed.

For example, initially you do 10 repetitions, and when they are completed you have completed 1 set. Because we are seeking endurance, we do more repetitions, and initially you would do 2 sets - you may exercise the quadriceps muscle and do 10 repetitions, resting for perhaps 5 minutes between each set. This was really important, and we were very, very concerned about fatiguing that muscle. We carried on like that from the start of the program to Day 11 - and you rested on alternate days. On Day 11 we increased the repetitions to 15 - still maintaining 2 sets - continuing with this until Day 21 and then we increased to 3 sets. Day 31 was the first day we actually increased the weight you would use. Again, this is similar to the protocol that Dr. Yarnell used with the exercise bicycle and swimming of laps. You didn't increase your laps on

that program until after four weeks - so again we were in the same ballpark. We must be doing something right!

Patients do this exercise program at home. We see them for the first 2 or 3 times, making sure that they are exercising the appropriate muscles, not bringing in auxiliary muscles because otherwise you are just going to be fatigued and that is defeating the whole purpose. Also, it is less time-consuming if you can do it at home and not have to come in for therapy, so it is a self-monitoring program too. As our program is rather flexible, these are just guidelines. Some patients were unable to take any weight whatsoever, so they started doing their exercises just against the resistance of gravity. That was all they could do.

Some people found that after a month of exercising they gradually started to feel some benefits. For others, it was three months. And it was actually six months before some other people started feeling any benefits. I must tell you that, although there is no quick fix, there are some people here who feel that they have reversed the advances of the post-polio syndrome. They certainly have more energy; probably one of the major things going along with this is that all of our patients are taught energy conservation.

So primarily, the thing I want you to remember is that our exercises are non-fatiguing, and that means you are not going to feel that you have worked out - certainly not initially. But you are going to require a great deal of patience and persistence.

**Nanw Roger, Physiotherapist:**

I want to give you a definition of energy conservation. As Barb told you the goal is to avoid fatigue and that is something that polio survivors seem to find very hard to do. I think possibly it may come from the time when we taught you - and I was one of those - to be athletes, way back thirty years ago.

Energy conservation is planning and organizing your activities ahead of time in order to minimize fatigue and increase the energy available to carry out the tasks that are important to you. You have to be realistic; you have to break up your tasks; you have to be flexible, take rest breaks, change your activities and distribute loads evenly. I had a gentleman who was carrying a brief case on one side and found he was really in a great deal of pain. I suggested putting the

things he had in one briefcase into two and carry one on each side, he did that and was just delighted with the difference. Carry your loads close to the body if you have to carry them at all; but it is better if you can have a cart and push things in shopping carts or a tea cart, put things on that and push it around in your home, or even at your work if you can possibly do it.

Use the best tools for the job and plan your work. If for instance, you have to do a bit of walking, make lists and save up all the shopping for that one area. Just do that bit; don't go tearing from one end of town to the other. Work at your best energy times. That is terribly important and I am going to tell you how to find this out by working out your own energy budget.

If you are fatigued check back to see what you did. You might have partied all night, or done something the day before, that took a bit more energy than you realized. Check back to see what was wrong, so that you can avoid combining that set of circumstances again.

Body mechanics is very important, and I would like you to get your friendly neighbourhood therapist or occupational therapist to teach you how to do this for yourself, because everybody has different problems in polio, as you have probably realized. If you can do a job sitting rather than standing, do it that way. Slide heavy objects rather than lift them. Have duplicates of tools or materials. For instance, housewives don't have to have all cleaning things in one cupboard and then carry them all around the house. You could have several caches of them in two or three parts of the house, so that you don't have to carry things around. That is true at work also. You can have duplicates in areas at work so that you don't have to carry heavy loads around.

These are all very common sense things, and it always surprises me that people don't think of them. I have learned such a lot from my patients, things they have worked out for themselves, that I pass on to others. I think that this is probably where the support group is most helpful. When you are talking in support groups you say what has worked for you and it might just work for somebody else too. It is a good way of exchanging information.

The thing we did most of all in energy conservation - we have a little form here - was to get people to budget their energy, rather like you budget your finances. Some people didn't like doing this at all - it was up to them whether they did or didn't - I guess some people don't like budgeting their finances either! I had them do these charts for the whole day, from getting up in the morning until the

end of the day - and filling out their activity in metabolic equivalents (mets). Now mets are a measure approximately equal to the 'resting energy equivalent'; that is, equal to the consumption of 3.5 millilitres of oxygen per body weight per minute.

I will quickly show you where we get these initial met numbers from. You multiply activities by the number of minutes that you did a particular thing and you get a total down here; if you do it for three days you get three totals. Now if you also noticed in your comments whether you were tired or fatigued, then you know that was probably a high consumption of energy for that day and you may have to cut it back. After the three days, I got people to average it out and take off some energy time if they found they were fatigued. Then they work out the amount of 'dollars' of energy that they had available for use, and spread it over the things they wanted to do, things for fun, things that they had to do - and people found this worked.

One of my patients had other complications too, lung complications. He found that he couldn't go out in the evenings, hadn't done so for years. One of the things he got from energy budgeting was that, by resting and cutting down his activity, he could go out with his wife and visit friends in the evening. That made a great difference to his life style, so he really enjoyed learning that.

I want to show you some of these things because I think it is interesting just how much energy you do use. You use 0.8 of a met sleeping, lying awake is 1, sitting in conversation is 1.2, shovelling snow is 11 to 15. Some things take quite a bit: dressing takes 1.6, driving the car takes 2, and mowing the lawn takes 5. Some of these you expect and some you don't. It often surprises people, how many activities require serious amounts of energy. Some things you just don't think of as exercise such as housework, gardening, painting and playing the piano.

Going up and down stairs with a 22 lb load at 54 feet per minute uses twice as much energy as going up with 17 lb at 27 feet per minute. So if you slow down and take less weight you actually are saving quite a lot of energy. These are the sort of things people find helpful. I give people these lists so when they work out their energy consumption they get some idea of the energy expended. Some idea of sedentary, light, medium and heavy work and how many mets are used up. If the task is not on the met list, the patient can work it out from their understanding of the task.

Once the patient has worked out their energy budget for three days, they can work out an average, cut it down if they have been fatigued on a particular day, and work out what they want to do, what they have to do, and what they would like to do. A lot of times this means a change of lifestyle, but if you are doing more of the things that you want to do, don't you think that it is worth it?

**Penny Filias, Respiratory Therapist:**

I am going to talk about respiratory problems with polio. George Pearson Centre has an outreach programme that has functioned provincially as the resource centre for many polio survivors. Respiratory therapy in and of itself consists of quite a broad range of therapeutics and diagnostics, so I am going to restrict myself to talking about mechanical ventilation which many of you are familiar with in the form of the iron lung.

Some of you have spent time in the iron lung, I am sure. There are two forms of ventilation: negative and positive pressure. The negative pressure ventilation which most closely resembles what you do when you breathe is the iron lung. Other forms of negative pressure ventilation include things such as pulmo-wraps, pneumo-suits and turtle chest shells. Essentially what they do is create a negative pressure around the thorax - around the chest - or perhaps around the entire body as does the iron lung and that helps you breathe. Of course the iron lung is not very portable and doesn't really suit our needs, so some of these other negative pressure ventilators are much more suitable for those requiring portability. However, negative pressure ventilation is not the most effective form of ventilation available. If you have a relatively minor problem, if it is something that you only require during sleep, then some form of negative pressure ventilation may be appropriate for you, at least for a period of time, and possibly not on a permanent basis.

By far the most popular and effective form of assisted ventilation is positive pressure ventilation. This works the exact opposite of negative pressure ventilation. The ventilator pushes air into your lungs and then allows you to breathe out naturally using the elasticity of your lungs. This is the most common form of ventilation that we use today. Again, there are several ways of providing this. One is through a tracheostomy, and that has both advantages and disadvantages. Some people use it as an intermittent positive pressure breathing unit with a mouthpiece. The newest positive pressure method of providing nocturnal ventilation is through a nasal mask which is very well



received because it is non-invasive - it does not require a tracheostomy. It is also only effective for nocturnal ventilation. You can't really use it if you require mechanical ventilation around the clock.

Most polio survivors with respiratory difficulty use a combination of all of the above methods. The ones that have little or no respiratory muscle activity or diaphragmatic activity, tend to use frog breathing during day while they are up in their chairs, a rocking bed while they are eating, and an iron lung or a chest shell or pulmo-wrap while they are asleep.

To go off the topic for just a moment, I would like to talk about diagnostics. One of the things we don't seem to have a lot of information on, is what your respiratory function is right now as a baseline value. Many people, who end up on some sort of assisted ventilation, do so after they have an acute case of respiratory failure and they end up in an intensive care unit on a ventilator. Then the form of respiratory treatment that they will go home on is determined. I would encourage all of you to have some sort of baseline pulmonary function screening done. The degree of respiratory involvement varies greatly, as do all the symptoms we have discussed here. When we see someone for evaluation, we do a pulmonary function test. We often find anywhere from a 20 to an 80% reduction in ventilatory capacity, but we don't know if that occurred in the past few years or if it has been like that for the past thirty years.

One of the things I would also like to talk about are sleep studies as a diagnostic tool. Sleep apnea is something that has only really been recognized in the past few years and every sleep study lab that I am familiar with is booked for a year in advance. Night time is often when you will run into real problems with breathing. You may feel that you are breathing well during the day and when, after having had several hours sleep, you wake up feeling more tired than you should be. Often this is because your respiration was greatly reduced while you were sleeping.

Pearson Centre has acquired some equipment that enables us to come into the home and do a modified sleep study. It is a very simple sleep study, where we hook you up to an oxymeter, which basically measures the oxygen in your blood. It's a little unit with a memory that clips on to your finger and you sleep with it all night long. If, when we print out the accumulated data on the printer, we find that your oxygen levels were reduced significantly while you slept, then we can get you in for a complete sleep study at the local sleep lab,

because the reduced oxygen levels may be an indication that you require assisted night time ventilation.

I don't want to go too deeply into mechanical ventilation because it does tend to be somewhat complex. There are a lot of issues such as safety, infection control, removal of secretion, all problems that are encountered by people who have decreased respiratory function. We do have an outreach programme for ventilator dependent individuals in B.C. where we provide service and maintenance on their respiratory equipment, as well as respiratory therapy home follow-up and assessment on a monthly basis.

### **David Lindsey, Orthotist:**

A certified orthotist is a professional who makes, designs and fits orthopaedic appliances, orthopaedic braces which are properly called orthoses. We make devices for basically all regions of the body with the exception of dental appliances. Orthotics is not a new concept. In fact, the earliest evidence of our existence dates back to the time of the ancient Egyptians.

The goal of an orthosis may vary quite a bit. they can be used to support, position or immobilize a part of the body and in some situations, they can be used to reduce pain. In more recent times, following the second World War, the field became more clearly identified, and in 1972 the Canadian Board for Certification of Prosthetists and Orthotists was granted incorporation in Canada. This is of great significance to you because you now know that the party you are seeking advice from has been properly trained and certified.

Today, most of the things we buy are mass-produced. Very little of what we use and consume is hand-made, that being too labour intensive to be profitable. Consequently, when we do have devices that are custom-made, their prices are astronomical. Unlike the rest of Canada, B.C. is the only province which does not have a universal programme to help cover the cost of orthopaedic appliances. What is so important about this level of technology?

I once had a gentleman come to me, who had been wearing a brace, the same brace, for approximately 35 years. I did an assessment and made a new device for him. Very roughly, with a bathroom scale, I measured the difference between the old brace and the new one: the old one weighed 12-1/2 lbs and the new one, 3-1/2 lbs, a 9-lb difference. This may not seem significant, but some

elementary arithmetic shows why this may have had a great cumulative effect him. An average person walks a mile which approximates 2110 steps. If you walk a mile with a device that weighs 12 1/2 lbs, you are lifting approximately 13 tons. In a three-mile day that is equivalent to 39 tons - so you can see the cumulative effect.

This man had been wearing the old brace for thirty five years. Many people are feeling the effects of post-polio syndrome 30 years after the event. I calculated that after thirty years this man had lifted approximately 432,000 tons. The new device, which itself was by no means light, would have reduced this by nearly 75% (312,000 tons), a very considerable difference.

### **Donna Dean and Jocelyn Malton, Myotherapists:**

We would like to share with you a new profession in Canada called myotherapy. Myo - is Greek for muscle; therapy means "fix it", so my profession is fixing muscle. We are another spoke on the wheel of health care trying to bring relief and help to people who are suffering pain.

Bonnie Pruden developed myotherapy quite by accident. She has spent 30 odd years in the field of physical fitness and exercise and in working with the medical profession. When she found people coming to exercise who were in pain she began to work on a method to erase or relieve the pain with exercise.

Myotherapy is a non-invasive technique and the only tools needed are your elbow, knuckle, fingers or thumb. That is why it is easy to accompany the treatment with education for the patient, and their family or friends, so they can carry on the treatments at home.

Treatments consist of three components - compression, gentle massage and passive stretching. Those three components make the treatment very successful. However, we can by no means cure disease. What we can do is bring relief from pain, and the frustrations that go with pain, for the short, if not the long, term. Myotherapy is probably the newest health profession in Canada. At the present time we are not covered by B.C. Medical Plan. Please note that we do not diagnose, and we treat only on the basis of a doctor's referral.

In myotherapy, treatment is team work. Persons have to want to help themselves to some extent. They have to care about what I am telling them,

take their newfound knowledge and tools home with them and work from there. We do not have any miracles up our sleeve. You may never be completely rid of your pain, but as long as we can get you to the point of relief and coping with it, we have done a lot for you mentally, spiritually and physically - the whole realm of wanting to live and be happy.

How many treatments you need is a very individual thing. You are a very special, unique piece of equipment and each person must be treated on that basis. However, the wonderful thing about myotherapy is that it can be taught to you, and can be carried on at home after the initial set of treatments.

The stretches we mentioned are passive, gentle stretches you can do anywhere, at home, at the bus stop, driving a car. They are stretches that re-educate a muscle that is in spasm to go back to its natural resting length and work for you. You never want to work through pain but the compression, gentle massage put the whole component group of muscles through a stretch which educates the muscle to stay out of spasm.

Trigger points, which we talk about in all our books, are simply irritable spots in the muscle. These trigger points cause muscles to go into spasm and they are flared by physical and emotional stress. Myotherapy helps you learn to keep the muscle relaxed and also helps to strengthen the muscle. If you would like to learn more about myotherapy we would suggest you read "Pain Erasure the Bonnie Prudden Way" which should be available at your local library.

#### **Gord Dunkley, Exercise Physiologist:**

I am here to speak to you today on a little research project that we conducted in cooperation with PPASS in Victoria. It was with regard to the use of a muscle stimulator. Since I started a large physiotherapy rehab and assessment clinic in Victoria, we have been involved in a number of applied research projects. Just to give you a little background on the study itself and what occurred. Last year, in Ontario, a doctor applied a muscle stimulator to a number of subjects who were post-polio syndrome sufferers. The muscle stimulator, which replaces a neural impulse with an artificial electric impulse, was utilized at very low intensities for a fairly long period of time. The subjects basically applied them overnight. In the case of our subjects here, they wore the muscle stimulators at night for a period of about eight hours.

We have a sort of conundrum with post-polio sufferers which is made up of a number of things. One, it appears that each post-polio sufferer is different - significantly different - and it is very difficult to prescribe one protocol that would apply to all. The other problem is, if we apply those rules to post-polio subjects, they don't adapt well. Where with normal subjects, when you put a workload on them they make an adaptation to that work load, and that is what training is. Well, with the post-polio person you can't do that. We get to a certain level of work and then, because of the 25%-20% rule, we begin to do more damage than good.

On the other hand you have a couple of other factors that come into the picture. One is aging, and the other is inactivity. In the human, if you are immobile and inactive, you deteriorate as a function of both aging and inactivity, i.e. your muscles atrophy. The other complication with polio survivors is that some of you have this syndrome that nobody exactly understands, how it works, why it works, how it happens, etc. - so we have some real problems. If we do too much we've got trouble, and if we do too little we've got trouble. And in between, we find immense variability.

So how are you to deal with it? You have the practical aspects of strength and living - thinks like walking up and down stairs, getting the groceries, getting in and out of the bath tub, going to the john, and all those kinds of things. You have a deterioration disease that is going on, and we have to try to arrest it or at least accommodate the change in the best way possible to maintain functionality. This means, in many cases, just trying to stay mobile and maintaining the ability to walk, to get up and down, and do things normal persons take for granted.

What happened down East was that they had this muscle stimulator and they reported some fairly significant increases in the ability to generate force in a muscle. We received results of this study, and were able to get four PPASS members as subjects of which two complied and two didn't - the two who complied were women and the other two were men, and I don't know what that means. Unfortunately, the total number of subjects involved in the Ontario study was five, and we had four subjects of which two complied. So the total number of subjects who have been exposed to this treatment is seven. With seven subjects I am unable to say that we got a major breakthrough, as you just can't draw valid conclusions from such a small group of subjects. But I can describe to you what happened.

We measured the subjects' force capability on a Kin Com machine, using the concentric or the shortening mode - which is simply an objective measurement of the ability to generate force. It is repeatable and reliable and you get all kinds of fancy graphs and ciphers but basically it yields a number. They received eight hours of treatment per day for six months, and then we measured them again to see if there was any difference. In one subject there was no difference; she had the same range of motion and the same peak torques at the same speed, so there was no difference. Her subjective difference was that she felt more stable. She has quite a significant difference between the left and the right leg, where there is quite an imbalance - and that didn't change. The only thing I can tell you is that there was no deterioration in the six months' period.

The other subject is ambulatory and has reasonably good muscular strength - much better than the first subject. This second subject had a fairly significant imbalance between left and right with about 20% difference. As a result of the muscle stimulation she got an improvement in the weaker leg, the other leg staying the same (although we applied muscle stims to both quadriceps) and she narrowed that balance from 19% down to 7%, so there was a bit of an improvement there. But it was only one subject and it could have been the "placebo effect", where she knows she is in a study and thinks she is going to improve, so she does improve. You know, if you improve because you think you are going to improve - that is not bad. The end result was that we did get some improvement, and subjectively she had a significant reduction in pain. All subjects remarked on the pain relief - and that must be of some value, I think.

The end result was, from the data we have, that we saw no negative effect, no deterioration. There was marginally inconclusive evidence on the positive side, so it is clear that more research needs to be done on this approach to muscle stimulation in post polio.

**Ariadne Sawyer, Neuropsychologist:**

This seminar is entitled "Take Charge of Your Life," because in it we will explore ways that will enable you to activate your own healing resources to help improve your health condition. You will find that you have a lot more power over your health than you think you have. The techniques that I will be discussing are not meant to supplant any treatment that you are currently engaged in, rather, they are to be used as an adjunct to such programs. I have

been researching and studying about the brain and its relationship to health and wellness for the past five years. I currently have a practice on Vancouver Island as well as on Salt Spring Island.

The basis for the concepts that I will be developing in this workshop are found in the fields of neuropsychology and psychoneuroimmunology. The study of neuropsychology is concerned with the relationship between the brain, the nervous system and behaviour. Psychoneuroimmunology adds the immune system as one additional interactive in the formula, to focus on how the brain affects the body's immune cells. Research shows that the brain and nervous system are intricately linked in the defense against infection, and that this connection is affected by thought and emotions. Thus, one's mental state can script the course of an illness.

There is a great deal of research currently going on in neuropsychology centres all over the world that are producing important findings related to the interaction of the brain and the immune system. It is now known that positive emotions help you feel healthier and that laughing perks up your immune system and acts as an antidote for the relief of pain. Conversely, emotions such as feeling out of control or powerlessness, fear, depression, hopelessness, or despair can magnify a health problem and may even make you sick. When you are beset with negative feelings your brain and immune system interact to create a closed loop. The brain sends out images; pictures of all of the negatives. The immune system receives the images and shuttles this information back to the brain. The body then provides the appropriate response and feels fatigued, depressed, powerless or ill. There is continuous communication going on between the brain and the immune system and you need to be alert as to emotions you are feeding into the system.

Examples of how this system works are most illustrative in the study of athletes. Sports psychologists have found that good athletes that were having a "bad run," were involved in a negative closed loop syndrome. Before an event or game, these athletes would start to do re-runs in their brains of how poorly they had performed, and all of the disastrous things they experienced that had occurred during their last event. It was found upon testing that their whole body was affected. Even the cells in their big toes got the message that said "Oh boy, am I stressed out, I'm going to mess up this ballgame." The outcome was predictable; usually a poor performance. Using this information, researchers proceeded to coach athletes to use positive emotions by doing positive mental rehearsals before participating in a sports event. The athletes

not only experienced success but it was additionally noted such positive imagining produced a discernable chemical taste in their mouth when they concentrated on winning, indicating immediate physical feedback.

Instead of being the victim of all of the adversities around you, you can actually use your magnificent brain power to take control of your life. The question merely becomes one of how to harness positive patterns. The brain has set thought patterns that are engendered by each one of us. They play repeatedly and once in motion create a domino effect within our bodies. You line up the dominos, push the first and all of the rest fall. In setting the stage for empowerment it is important, first of all, to reduce your stress level. If you have a program that works for you then you are going to feel healthier and a lot more empowered. There are a variety of stress reduction programs, but one of the most successful techniques I have found is Autogenic Training. The technique was originally developed by two doctors in Europe and has been enthusiastically adopted in the sports field and is even becoming common place among employees of large multinational corporations.

When you are doing any relaxation exercise it is sometimes hard to give in and let yourself go. It helps if you can envision a favourite place; on the beach or floating on a cloud, or wherever you are happy. Get in a comfortable position and imagine yourself there. Include in your image all of the details that you would find if you were really there; colour, sound, smell, taste and feeling. Much of what I am going to say is repetitive.

Relax and close your eyes, and let any worries or thoughts that you have float out and away from you. Focus all of your attention on your head. Your head is warm and heavy. Feel your head, warm and heavy. Focus your attention on your head and feel your muscles relaxing. When things get tense all of the muscles and cells in your body tighten like hundreds of tiny fists. You want them to open up, just like flowers opening towards the light. Your head is warm and heavy. Now move slowly to your face. Feel the muscles around your eyes, face and mouth relaxing, letting go, warm and heavy. Feel your face warm and heavy. Every cell, every muscle, every nerve, warm and heavy.

Go into your neck. Feel your neck relaxing, warm and heavy. Every muscle, every nerve, every cell, warm and heavy. Your neck is warm and heavy. Your shoulders are warm and heavy, relax your shoulders. Put all of your attention on relaxing your shoulders, warm and heavy. Your shoulders are warm and heavy. Your arms and hands are warm and heavy. Feel your arms and hands,



warm and heavy, warm and heavy. Continue in this manner throughout the rest of your body.

When you get to your toes go back and see if there is any part of your body that is still tense. People have tension in different places; some in their shoulders, some in their necks, some in their stomachs. Go to that part and say, warm and heavy, warm and heavy, warm and heavy, until you can feel that part relaxing. The message that is going from your brain to your body is relax and feel warm and heavy. Let go of tension, feel warm and heavy. Take a moment to feel your specialness. Are there any nice messages that you want to send to yourself? Messages of love, caring, or applause? Spend time with yourself sending those messages and be aware that even the cells in your toes will receive them. The messages go through special chemical relays, called neurotransmitters so that every cell, every muscle, every nerve will be relaxed.

Autogenic training can be used to set the stage for improved health. Last year, for example, I had seven people that were able, with their doctor's approval, to stop using their blood pressure medication. They had reached the point where they could actually lower their blood pressure and keep it lowered at a healthful level. If you can add the power of your mind to your medical treatment, you will find that treatment to be more effective. In essence, you are adding something to whatever medication you are taking, or treatment you are receiving.

Norman Cousins, the well known author, states that people can become survivors of diseases. You may accept the diagnosis, he notes, but have a blazing determination against the verdict. You can actually empower yourself to feel better and in the process create more options. The other way, where you remain passive and feel hopeless, leads to fatigue, depression and a weakening of the immune system. It is important to become personally involved in the maintenance and direction of your own health. Work with your doctor and help your doctor help you.

I think another example would help to illustrate the point. I once had a lady referred to me that had cancer. Her doctor hoped that I could help her overcome some of the negative effects she was experiencing with her chemotherapy treatments. Because of her experiences, she would anticipate pain and discomfort surrounding the chemotherapy, and would become violently sick and bedridden two days prior to her treatment. She would remain this way for several days following. You can imagine what was happening to her

immune system. It had not only the normal problems to overcome that typically result from chemotherapy, but had the additional burden of conquering the psychological attack that had been surmounted against it.

We worked together using the relaxation techniques of Autogenic Training. Before each treatment she would empower her immune system to work positively with the chemotherapy. She never became overly fond of chemotherapy, but reached a stage where she experienced only a slight malaise after each treatment. Also, she no longer needed to take to her bed days before and after the treatment. The point is, that if you can create relaxation within yourself then you have it there as your ally whenever you need it. I should point out, however, that you can't simply take a magic pill and immediately go into your relaxation mode. Like everything else, it takes time and practice. You have to establish a blueprint in your brain and that takes commitment and work.

Along with establishing a pattern of relaxation, it is also important to look closely at how you are communicating your health concerns to others. How effectively, for example, do you communicate your needs to those concerned about your care? How about yourself, do you understand what those needs are? Clear communication is important, as faulty communication or lack of communication aggravates stress and subsequently your health. Before you can communicate effectively with others you need to be completely clear as to what those needs are. Once you understand your needs, as they relate to your health, you are then in a better position to make those needs known to others. Don't forget you are in the driver's seat, it is your life and you need to make it very clear to people what you want and what you expect.

Because of the special needs that Post Polio Syndrome demands it is important to be clear and assertive in all communication concerning your health. Be careful, however, not to confuse assertiveness with aggressiveness. They are not synonymous. Aggressiveness will only serve to isolate and hinder communication.

Communication involves interaction with another personality and your message will not be clear nor appropriately acted upon if you introduce aggressiveness, hostility, blaming, or an air of inequality about your manner. Assertiveness means being, first of all clear with yourself, and secondly clear with others as to exactly what you need to do to maintain and improve your health. If that means frequent resting or not being able to get something done immediately then so be

it. Tell yourself and others that you operate in two speeds; slow and slower, "which do you want?"

How do you know when you are getting your message across? A good way to test your success is to note what response you get. People's response to you is based not on your actual intent, only you know that, but on their perception of your intent. Those perceptions are based on people's previous experiences with the situation at hand, and it may be that they simply have not dealt with the kind of message that you are giving. If you receive an inappropriate response to your message, it does not necessarily mean that you are dealing with a blank wall, or an over-reactive person, or even someone who is hostile.

Sometimes you need to try another approach or to state your concern in another way. Try again and be flexible enough to change what you are saying. There are people that you will come across who are so stuck in their patterns that communication is rendered impossible. There is really not much you can do in such an instance. Do the best that you can and then let it go.

Once you are aware of your needs and are clear as to what it is you want to say, you should then be firm in your resolve. This is not always easy to do. Many find it difficult to remain firm in the expression of needs. We are often pressed into saying "yes," and rather than being thought of as uncooperative we acquiesce, and so overextend ourselves. This is relatively common and in fact is noted by George Solomon, a psychoneuroimmunologist with the UCLA Medical Center in California.

In working with Aids patients, Solomon can determine longevity by noting his patient's willingness to accept society's precept of overextension. He has an 85% success rate. Upon their first visit he asks the patients the following question; "If you are feeling really ill and a friend calls you up and wants you to move them today, what do you say?" If they say, "right, I'd be happy to help you move," he figures that these people will last around seven months. What they are doing is saying "yes" to the friend but "no" to themselves. They are robbing their bodies of the need for rest that is important for maintaining a balanced profile. I have noticed a similar behaviour among the cancer patients that I work with. They typically have a hard time expressing themselves or standing up for themselves. Health, particularly when you are ill, demands balance and harmony.

Just one more thought on communicating and the problems I think some people might run into. There are special communication concerns with respect to your family. If you have raised a family and have worked for many years and are for all intents and purposes quite normal, then suddenly find yourself ill again and no longer able to do the things that you used to, you may find a lot of fear being expressed in your family. You have to be very gentle with your family as they will with you.

You are all dealing with fear. Diagnosis is difficult and prognosis uncertain. This causes some families go into partial denial. They don't want you to be ill again and they think that if they are forceful enough you will somehow rally and pull through. You have to set strong guidelines and make it clear what is happening and that what you are experiencing is real. If they are forced to operate in a fog, it becomes difficult for them to know how to help you and a lot of resentment can build up and create serious dysfunctions within the family.

The last thing I would like to address is the topic of negative emotions. Emotions such as anger, fatigue and depression are three commonly expressed feeling which can directly affect your health. I have certainly had more than a passing acquaintance with these feelings myself. When I was fourteen I was studying to be a professional ballerina in Mexico. I was about to perform my debut in Swan Lake and I became quite ill the preceding afternoon. What I did not know at the time, was that I had contacted Polio. I knew that I was very ill and that my legs were paralyzed.

My image of the time is still quite vivid in my mind. I remember sitting in a wheel chair and all manner of doctors were standing around looking at me and shaking their heads, saying "she'll never walk again, she's been too badly damaged." I felt an anger welling up inside of me and decided there and then that I would walk again, no matter what it took. I was actually able to use anger in a very productive manner because I turned it into a driving force of energy. I got up and fell down, I took another step and fell down, but I eventually walked. All during my ordeal it was anger that was pushing me in a positive direction.

Almost anyone who has had a serious illness will experience anger at some point. It is a natural stage in the grieving process, something you need to go through, so don't be afraid to allow it to happen. This does not mean that you have to associate with it. Such emotions do not need to be used as destructive

forces which wreck havoc with your immune system and create inviting conditions ideal for development of diseases.

Actually anger affords you a wonderful opportunity to see your energy at work, it can be a powerful force if you use it to your benefit. Use the energy derived from those emotions, and channel it in a positive direction rather than letting it tear you apart. Just think, more energy equals better health. If you choose to let anger control you, then depression and fatigue will take hold and can easily become a pattern in the brain, a pattern that once established becomes difficult to change. Once an emotion, such as anger, has served it's purpose let it go. Don't use it to push yourself beyond your capabilities. Learn to know your limitations.

Earlier I discussed the importance of communicating with yourself. In the case of anger, ask yourself a number of questions; how do I relate to anger? How do I use it, do I use it against myself, or against other people, or as a tool to help me? Is the way I use anger a positive or negative thing for me? The next time you are angry, chart the course of your anger, notice how you respond and then work to change any negative patterns. You are your own researchers, only you have the power to change your patterns. Once you understand how anger affects you, you are in a position to be able to do something about it. One of the things you do is neutralize your anger.

I was visiting the home of one of my clients and noticed a magnificent section in her garden that was more prolific, colorful and healthier than the rest of the garden. I asked her if she did anything special to that part of her garden and her response was most interesting. She said the "beautiful" part of the garden was the spot where she would go to dump all of her anger. She would imagine it going through her body and into the ground. You would think that with all of the negative energy going to the garden that it would be rather snarly looking. Instead, it obviously thrived with the energy that it was receiving. She ended up with a perfectly beautiful garden and in the process was able to neutralize her anger.

Old patterns of course are not always easy to break and take conscious effort and vigilance on your part to deal with them. I have another client who has chronic health problems but is much healthier when she assumes charge. Her stumbling block is doubt and despair. She has learned to deal with her situation by making a caricature of her doubt and despair. She has named the itinerant, Aunt Ninny. Aunt Ninny blows kisses of disparagement her way until she is

able to get a foot in the door. She then barges in, grabs a cup of tea and settles herself down to talk about how terrible she feels and woebegone she is. At times it is too difficult to bodily pick her up and throw her out, so Aunt Ninny gets the cold shoulder treatment. The effect is not immediate and Aunt Ninny proceeds to talk her ear off with useless gossip. In time, however, she becomes weary of being ignored and goes quietly on her own.

Sometimes it is effective to alter the mode or the dimension the old, negative patterns operate in. Start by visualizing one of your negative emotions. Put it into a three dimensional context. If you could put a shape to it, what would it be? What color does it have? Add a sense of smell to it. What kind of sound does it make and what does it feel like? Once you have this image in your mind, change it. Change the shape, colour, feeling, sound, and smell. Get all of your senses involved and make the changes positive ones. In the literature this is referred to as Submodality Change.

Every time the old pattern starts to play, go through this exercise, and change the mode that it works in. If you need just a quick "pick-me-up," use the Six Second Quieting Response. Smile inwardly and say "alert mind, calm body." Then take a deep breath and while exhaling slowly, let your jaw, tongue and shoulders go limp. Feel a wave of heaviness and warmth flowing through your body and toes. Resume normal activity. This will give you a chance to shift gears.

A vital component in taking charge of your health is humour and laughter. The brain loves it. It needs stimulation and to have something interesting to do. If it gets bored, it starts playing old re-runs of all the most horrible experiences you ever had in your life, for the 150th time. One lady I worked with told me that every hour she would say "Mary, it's time for a little chuckly" and then she would laugh. Incorporate laughter into your everyday routine, laugh for five minutes, tell funny stories or funny jokes, watch funny films. Laughter will do wonders for you. It releases endorphins from your brain which eases pain. It makes you feel good all over and gives your immune system a little boost. It helps exercise your insides, sort of like internal jogging. A wonderful book to read in this venue is *Laughter is the Best Medicine*, by Norman Cousins. It is excellent reading.

There is a great deal of research being done on the mind/health connection. Dr. Bernard Siegel of Yale University has done a lot of work with exceptional cancer patients and notes that it is those who work toward creating a climate for

healing that are more successful in reaching their goal of better health. Also, Dr. Lewis Thomas of the Memorial Cancer Sloan-Kettering Center in New York, states that the cure for cancer will come when we stop becoming victims of our circumstances and instead allow the vibrancy of life to flow through us. This is a powerful statement from one who is so well known in the cancer field. What we need to do then, is change our focus from "poor me, look what life has done to me," to living a meaningful life which is looked at as full of challenges and opportunities.

A particularly interesting finding has come from the research of Dr. Karl Pribram, chairperson of the Neuropsychic Research Laboratory at Stanford University. He has been concerned with analyzing how the brain interprets reality and the difference in the brain's perception between reality and imagination. His findings show that in terms of the brain's view of life, there is only a one percent difference between reality and imagination.

Think of all of the fun you can have with your imagination. You can create your own inner climate so that bugs, viruses, fatigue, depression and all of the negatives that harm your health, will have a hard time taking root. I was watching a Bill Cosby show not too long ago, in which he was trying to ease his youngest daughter's cold. He told her that "cold bugs are party animals. They are always looking for a place to party, but if you take your vitamin C and drink your orange juice, the cold bugs go ugh! I don't like this place, I'm getting out of here, I'm going to find someplace to party! I think it is exciting to be at this point in time. We are able to see that we can change, we can take charge, we can use positive emotions to become healthier and more empowered.

In closing I would like to say that each one of us is full of a lot of untapped power, talent and potential. We all have options, but it starts with you. It can be an exciting time, as all sorts of things can start opening up for you once you take control of your life. Not all at once, but little by little. Sometimes it's a matter of keeping on trying, getting up and falling down, taking another step. Make the most of your life and have fun.