

Weight Management: A Polio Perspective for Women

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INTRODUCTION

Limited movement and muscles, now too weak to carry extra pounds, are realities which contribute to making weight management a problem for many women who have had paralytic polio. Particularly those who are experiencing slowly progressive muscle weakness resulting in pain and fatigue, commonly referred to as "the late effects of polio." For some of us, the medical recommendation most dreaded and frequently heard is "Don't gain weight!" or the oxymoron, "Lose some weight but conserve your energy." For us this challenge is the most painful part of our polio lives.

How many times have I been too discouraged, too exhausted, too empty to care about how I was eating? Many. How many times have I wept over my bulging belly and the aches in my arms and legs which came, in part, from lifting and supporting my weight? Many more. Have I hated this part of my life? Yes! Do I like food? Enormously. Have I been able to solve this dilemma? For today, yes.

Because of that final "yes" I offer you a story of hope, hard work and success which is just as possible for you. What you will read is the personal adventure of a woman with residual paralysis from polio who has had to restrict activity from age 6. I have no credentials other than my own experience. I have only the medical or nutritional knowledge which I have read, or been told by professionals who have helped me along the way.

What I have discovered is that eating and movement are highly personal affairs which no one can possibly prescribe for anyone else. If others do try to tell me exactly what to do, I usually find it doesn't work for me for very long. That's why doctors seem to equivocate when advising us on what we should do to manage our weight or undertake appropriate exercise. Our own bodies are the ultimate experts. There is good, reliable nutrition and exercise information available to us through doctors, dietitians and other health professionals, but only we can make the knowledge they have, work in our lives.

I invite you to join me in looking at the process of learning again to eat/move/rest. Actually this is something that most health conscious adults need to do. The misinformation we learned about food and exercise as children and teenagers is embedded deep in our psyches causing weight management problems for many adults. We, people with polio, who have experienced a major disruption in our natural cycle of food/activity/rest need to reeducate our bodies and minds with doctoral level courses in different practices. And because we need to be our own teachers, we require lots of reliable information, many opportunities to experiment and unlimited support from friends and knowledgeable people, as we investigate what will work for us.

Finally, this essay on eating is not a prescription for losing weight. If you have heard me so far, you understand that what works for me may or may not work for you.

Even though we have a common struggle, we are very different people. Some of my strategies might be helpful to you but with your modifications. You will need to write your own prescription.

And I offer you an important warning. I have never successfully undertaken the task of losing weight or staying with a program of exercise without the supervision and guidance of health professionals with substantial credentials. When losing weight and exercising we all need to be monitored by a doctor or clinic. Doing it alone is like playing Russian Roulette with our bodies.

The excitement in undertaking this eating/exercise adventure is that it gives you another chance to learn more about yourself, about your eating and activity patterns, about your beliefs, so that you can refine and improve your daily practices. You may or may not need to lose weight. The chances are that if you become reeducated about eating and movement, and if you need to lose weight, you probably will.

This approach is different because it explores the problem from the polio perspective. One reason that dieting has not worked for you, a woman with polio, is that you are different. Your reasons for being overweight are probably different and the strategies you need to lose weight are different, because your body is different. In the first chapter we will meet a group of polio women who have identified themselves as having weight management and mobility problems. We will try to understand the problems from their perspectives. Perhaps you will hear some of your own issues expressed through their words.

"We" are 13 women who found me with the help of Jessica Scheer and the Polio Society of Washington, DC. At a regional polio conference, they introduced themselves to me because they were willing to talk about their weight management issues. Through follow up telephone conversations they responded to the questionnaire which I gave them at the conference.

The voices of those 13 are echoed by the written responses of 13 other women who replied to the same questions, sent to them through the newsletter of a polio support group in the Philadelphia area. Therefore, the total group of women questioned was 26.

Geographically the combined groups represent the states of Virginia, Maryland, Delaware, Pennsylvania, New Jersey and the District of Columbia. By chance, I talked with a diverse group including African-American, Asian, and Middle Eastern backgrounds. There was religious as well as cultural diversity: Protestant, Catholic, Greek Orthodox and Jewish faiths. From many perspectives they face a seemingly impossible problem.

"It's a big problem because for the last 5 years I have been a vegetarian (I eat no meat) and I still gain weight. My cardiologist tells me that I have very high cholesterol, so I have been taking even more care with what I eat. I eat no fat now. I only eat what I prepare. I have added more than 20 lbs. With all these adjustments my weight doesn't go down. Nothing is working."

These are women who have lived "normal" lives by anyone's standards: married, (11/13); raised children, (8/13); had careers, (11/13); live with others, (11/13). They have cooked the meals, run the errands, tended the gardens, fixed the repair problems and cleaned Cape Cods, split levels, ranchers, basement walk-ups, apartments and three floor houses. Even today they are very healthy people. Only 2 of the 13 have had conditions not related to polio; cancer and diabetes.

Polio dictates their age range (46-72) with a median around age 60. They contracted the disease anytime from infancy to young adulthood, so all have been making polio adjustments for years. All of them have residual leg paralysis, but 10 consider themselves ambulatory with some kind of support; 9 are braced, 9 use canes or crutches, and 6 ride on scooters or chairs part time. Three women use a scooter or electric chair all of the time. In spite of these limitations all of them have figured out how to get around. Driving a car or van is the answer for 11; some use hand controls.

Polio has effected their daily lives and still does. *"It's a struggle because I consume more than I expend. Mobility is an issue. Eating is something that I can do well without pain and fatigue. Food is a reward for all things; a soothing friend for all moods, sad, angry, happy; a celebration at the office...For 34 years I have had a battle with weight. At age 20 I was athletic and thin, even having four children...and then I got polio."*

A few, like this woman, have experienced weight management issues since they first had polio. Now, the others, who for a long time have been able to compensate for activity limitations, are becoming increasingly aware of weight loss struggles as they experience this later period in their polio lives. They all reported one or more of the following "late effects": breathing problems, arthritis, elevated blood pressure and/or cholesterol, sleep apnea, new muscle weakness, shoulder/back/arm/leg pain, fatigue, and equilibrium problems.

It isn't hard to relate to the frustration and fear of the woman who said, *"I can't fit into my clothes any more. Over the past four years I have gone up two sizes. These are the reasons: since retirement I have access to the refrigerator; I used to do limited walking from the van into buildings but can no longer; I bought a power chair which raises my body, using my arms less; my metabolism has changed. The weight is distributed in my torso which makes it difficult to raise myself. My arms are getting weaker."*

They have both overlapping and different views of the problem but with one common theme. All women in both groups say they can't be as active as they used to be. Of the 26 respondents in the combined sample, 13 are consciously trying to exercise. Many (10) swim but piano playing, painting, bicycling, yoga, walking and physical therapy exercises help the others expend some energy on a regular basis. *"In spite of pool exercise, weight isn't coming off,"* one woman reports.

In addition to the new muscle weakness that is limiting activity, many are experiencing the fatigue that can accompany the late effects of polio. For some this has required a radical change in life style. Among the 11 members of the interviewed group who are career people, two are now semi-retired and five had to take an early retirement. One of the workers talked about the fatigue problem. *"On the job I was drinking tea and coffee to stay awake and I was eating to get energy."*

While mobility is the weight management issue common to all of the respondents, it isn't the only reason cited. Other reasons for gaining weight included eating behaviors, social factors, and biological and psychological variables. However, polio related factors entered into most of these other weight control issues.

Eating behaviors were discussed frankly. Although many are on a regimen of healthy foods some admit, *"Anything that is wrong to eat, I like." "I choose the wrong kinds of foods." "I can't stop eating until I am stuffed to the gills."* One woman reflects a polio perspective. *"I don't have the energy to prepare nutritional meals. It's easy to fall into bad but enjoyable eating habits."*

The ages of the women signal metabolic and hormonal changes which impact weight control. Women who had polio are encouraged to use estrogen because of our vulnerability to osteoporosis after menopause, but that medication and others (used for

pain and depression) sometimes enhance appetite. Other biological issues discussed were sensitivity to food cues (sight and smell) and genetic factors. Four women said that they have inherited a predisposition to being overweight.

Social factors raise other polio issues. With restrictions on recreational activities, women look for pleasures they can enjoy with friends and family. *"My husband and I like to travel around on Sundays, go to a buffet. It's hard not to eat." "I so enjoy going out for dinner with my friends, eating the bread and butter and desserts."* These women do not have the option of physically active vacations, using up calories with games of tennis or as walking tourists. For them vacations mean riding on scooters and going to restaurants. *"Vacations are killers for me. Eating out is the hardest thing!"* For polio women, eating out removes the physical challenge of cooking and cleaning up and it's something they **can** do with other people on equal terms. The social advantage wages war with the temptation of food, attractively and abundantly served, with no energy expenditure on their part.

More complex and more deeply rooted in the polio experience are some of the psychological reasons reported for weight problems. *"It's too hard to do. I feel like it's another thing I can't do, along with so many others."* In addition to powerlessness, several women spoke of the painful loss experienced with giving up food. *"I know the less I weigh the better I can move, but I have had to give up so much recently (my job, independence etc.) that one pleasure I still have is enjoying meals, snacks, desserts. I can't give up everything!"* Heard in this woman's desperate cry is her fear of losing control, *"My problem is that I can't let go. I can't give up everything. I need to relax..."* Her words that followed expressed anxiety about the future, about how disabled she might become ultimately, particularly if her weight continued to increase.

The honest voices of these women reveal their frustration, discouragement, sadness and fear, in addition to the physical pain and/or discomfort with which all overweight polio women live. And like everyone else, they live in the real world of stresses, transitions, and crises. References to stressful family lives, past and present, were part of our discussions: death of parents, divorce, raising children as a single parent, in addition to illness. Through out it all, these women have managed.....everything but their weight.

They have tried dieting, most of them many times. Over a dozen diets were mentioned with the commercial diet center programs used most frequently. So many of them lost weight and then gained it back, plus more. Of the group of 13, one wanted to lose 10 pounds, another wanted to get below 200 pounds. Most of the others wanted to lose 20 to 30 pounds. They have come to the conclusion that losing weight is more difficult than maintenance because they all feel overweight and, without vigorous exercise, they think that they can no longer make the adjustments required to lose those extra pounds.

Those of us resonating to these life shattering problems, find it difficult to remember that not all polio women have weight management issues nor do all who are experiencing the late effects of polio automatically gain weight. But for those of us who have, the challenge seems as great as that of recovering from initial polio. It is a problem because it is happening to women who know and practice nutritious eating habits. It is a problem because it is happening to a woman who remembers that she was "*a skinny, skinny kid. I lost weight prior to finishing school. I lost weight chasing my kids around. Now I have tried and tried, forever, to lose 15-20 lbs. I can't because of the fact of immobility.*" It is a problem because we all know that weight makes our difficult lives more difficult. And we all fear that this problem could get worse.

We need to ask ourselves, what do those others who have not gained weight, know or do that we don't know or do? The answer is the topic of this work. The chapters that follow will explore the complex experiences we all have had with polio, mobility and for some of us, food. By teasing apart a complicated, sometimes shadowy and sometimes painful personal story I have discovered connections which have been enlightening and have helped me to make changes in my eating behavior. I hope you will allow me to use that experience to clarify my discussion and to connect you, the reader, with your experience. Throughout I will quote in italics the wonderful women who contributed so much more to my understanding of the eating/movement problems which we share.

Some polio women do not and possibly will not have to struggle with these weight management issues because:

- of what they knew or learned, early on, about their bodies;
- of choices they have made about how to expend their energy;
- of how they have responded to their polio experience;
- they didn't have to deal with a combination of life events which can trip the precarious balance of a polio person and upset the equilibrium of even the most stable and wise.

However, if you the reader are still reading, you do have concerns. In responding to your needs I will assume that some of the following characteristics describe your polio experience, giving us common ground on which to stand (sit or roll.)

As polio women we are people with residual paralysis, probably affecting at least the lower limbs. We have mobility issues because of muscle weakness; we are not likely to run, if we walk we do so with effort, and some find prolonged standing impossible. We may be experiencing on-going loss of function. We are not likely to be able to sustain 20-30 minutes of aerobic exercise, the duration required to begin to use up extra calories. (1,p.12) We may be confined primarily to our homes with less physically active interests and more access to food.

The polio person possibly has fatigue issues. When we feel exhausted we may be in the habit of going to food for quick energy. We need to sleep and rest more than other people. Because of body pain and lack of activity some of us experience sleeping problems.

The polio person may have eating issues that are psychologically related to the initial trauma and the emotional pain of living with polio. Some of those issues might have to do with the loss of body function which we have experienced. We may have trouble getting in touch with physical and emotional pain which we have learned to deny because at one time they were overwhelming. We may experience isolation and accompanying emptiness because socially we have not coped with being different. We probably have issues around the dependence/independence continuum. All of us experienced powerlessness initially, and have spent a lifetime trying to regain control. And for women particularly, there could be self image issues connected with disfigurement.

The polio woman is coping with the slowing down of systems because of aging. Caloric needs drop by 10% each decade after age 50. (2,p.255) And hormonal changes will have their impact if they haven't already.

Many of us have atrophied limbs which means that too much of our weight is distributed to other parts of our bodies. Some of us have to carry extra weight in braces, which needs to be compensated for by less body weight.

And we can't even follow the doctor's recommendation to turn down the thermostat in cold weather requiring the body to burn more heat (calories), because the majority of us have circulation problems. (2,p.275)

Oh well! We haven't let the impossible stop us in the past so let us move on to a first step in finding solutions, the telling of the Polio/Food Story.

How has wisdom been transmitted over centuries of human existence? We all know that story telling is the universal mode of passing on generational knowledge. But the act of story telling does something for the teller as well as the audience. In creating the story, the teller must generate ideas, mold them into a meaningful form, translate them into words all the time making sense out of his/her own experience. This significant expression of human creativity, the telling of your story, can be a powerful tool for understanding who you are and what you need. I recommend it as a place to begin your commitment to change your food history. Your story provides the starting point on which to build your strategies for change.

Knowing my food story has been essential to my success. I have, over time, burrowed deep into my memories to determine the roots of my eating behaviors. I know that they are genetic and experiential.

My parents were healthy and active. My 5'5" mother prided herself on weighing 122 lbs. every day of her adult life, "The weight I weighed on my wedding day," she boasted. She played sports in college, tennis as a young adult and she loved to walk. My father was tall and athletic (cheerleading, tennis, crew) but he was also a naptaker who loved food. His favorite foods were meat, potatoes and gravy, and desserts. Mother loved Coca Cola, sugared tea, buttered toast and marmalade.

Nobody in Mother's generation had weight issues; but, my paternal grandmother, aunt and uncle were all heavy adults and my father dieted from time to time. Guess whose appetite I inherited? Genetics do determine our physical shape and size. From both parents I was predisposed to be taller than polio allowed me to be. From both sides I inherited a metabolism which goes with physically active people. But because of the effects of polio I have had to learn eating practices which go against my genetic plan.

Why is this important information for me? Because when I struggle with food and fail, I need to **fully** appreciate **all** of the reasons why it is difficult for me to lose or maintain weight, so that I don't undermine myself with moral punishment when I slip.

Beyond genetics we learn how and what to eat from our families. Baby pictures prove that I was a rolypoly, adding hungry fat cells to my body very early in my career. The baby book documents a rigidly scheduled food regimen which had little to do with my hunger or lack of it. What we are taught early on really sticks (to our ribs!)

There are two parts of our early eating education: 1) what we are told by those feeding us, i.e. "Eat your vegetables! They are good for you," "Clean your plate," "Try everything," and the moral heavy weapon "Think of those poor starving Armenian children"; and then 2) what we saw our adult family enjoy eating, i.e. a box of chocolates in one evening, lemon meringue pie, junk food snacks, homemade fudge. During my living-at-home years a salad meant tuna, chicken or egg with lots of Miracle Whip and a

little celery. It's good to know that much of our eating behavior is learned because we can relearn it!

Meals were an important daily event in my family. We had a formal dinner in the dining room each night, and we usually sat together to talk and share the other meals. Going to a restaurant was a big family treat, even to the cafeteria line at Horn and Hardart's. I learned to associate eating with the most satisfying social experiences of the day.

Our early eating experiences effect our eating behavior. Studies suggest that there is a genetic preference for sweet food because this concentrated source of energy initially was important to survival. Infant taste buds carry the message that sweets are most satisfying. And as soon as I was old enough to understand, I was programmed by adults to perceive sweets as rewards. However, our taste for different foods can be manipulated and changed by subsequent experiences. (3,p.101) Once I got sick after eating caramel covered popcorn. To this day I can't stand the smell let alone the taste.

But beyond simple preference, foods and eating can become complicated by intense feelings which are associated with specific events or situations. You need to know what those are in your life. For me, eating became a major control issue when I was 4 or 5 and I watched, in fear, the battle of wills fought out between a relative and her baby over his consumption of dinner. At worse, she straddled him while he was flat on his back on the floor. He was screaming with rage as she, in anger, forcibly spooned the food into his mouth. I mislearned that eating has nothing to do with choices.

Another food event happened when I left the polio quarantine hospital and was transferred temporarily into a semi-private room in a children's hospital. Under those circumstances I was able to see my parents for the first time since the ambulance men had kidnapped me from my home. I got hysterical, crying out the rage, fear and sadness of the previous three weeks. To stop the tears the nurse brought me a big bowl of strawberry ice cream. From that moment ice cream has been my comfort food, for life - although I never choose strawberry. Because of these powerful emotional events, I have had to reeducate myself to understand: 1) that I shouldn't eat unless I'm hungry; and 2) that I eat certain foods, not because I am hungry but when I am having specific feelings. Those foods need to be consumed with caution.

My attitudes toward food, my weight and my appearance were shaped by my mother who selected and prepared three meals a day for her family. Although not discussed directly, I received this message: because of my awkward gait and withered leg, my general appearance was very important. So beyond the issue of carrying extra weight, I mustn't get fat because I need to "look good." In adolescence I was bought girdles and waist cinchers to control the fat . And I was always on a diet. When I left for college Mother's present to me was a bathroom scale.

My eating history, documented over time, also teaches me about important patterns which, when understood, help me predict and override my habitual food responses. My patterns have to do with the "yo-yo" game of weight loss and gain, and with specific kinds of experiences and feelings which are related to the gains.

In 1944, aged 7, my polio doctor told my mother that I mustn't carry any extra weight. As my number one supporter and caregiver, she took his advice very seriously. For the next three years, in and out of a "school for crippled children" and three return hospitalizations for major surgery, I was having intense feelings which I tried to manage with food and I gained weight. Mother tried to control my food as best she could but I would find ways to get more than my inactive body could expend in energy. So the pediatrician prescribed benzedrine (later Dexamil) whenever I got too heavy.

I was at my best childhood weight at age 13 when a broken leg and a traction body cast kept me out of reach of food for two months. From that experience I learned that even with complete immobility, if I needed to lose weight, I could. By 1959 I was at an all time high weight, being fed at college, by the institution. They provided the right food for active young women on a large, hilly campus but wrong for me who became even less mobile because of distances and terrain. After college I went back to diet pills and lost weight.

By 1961 I gained even more weight for another thematic reason; separation from my family. As I had discovered in college, separation brought back childhood hospital anxieties which intensified with age. For relief I ate enormously for a year when I was living in South America, again having my meals supplied and prepared by others. Upon return, I went on pills and lost weight. Again, in 1963, I left home to work in Chicago. Another separation and I gained weight. This time, by the grace of God, I decided that I couldn't depend on pills any more. I dieted without them and lost weight.

I gained it back in graduate school, another separation with institutional feeding. I used a Ladies Home Journal diet plan which worked temporarily because I had to **commit** myself to goals and mail in my meal record and weight to the sponsoring organization. In 1973 I traveled to the Middle East to attend my younger brother's wedding. I was 36 and unhappily unmarried. After this familial separation, when I returned home Weight Watchers helped me lose some pounds. In 1984, the biggest crisis of my life, the death of my mother from Alzheimer's disease came at a time when I had just stopped smoking. I joined a weight loss program sponsored by a local university, with limited success, mostly due to the leadership component who were not properly trained.

In 1988 more transitions came with my separation-divorce and the painful death of my father. By this time I realized that weight management was, for me, more complex than calorie counting and had little to do with will power. I knew I needed a multidisciplinary approach to understanding and managing my weight. With the combined help of a psychiatrist, a nutritionist, a food therapy group and multiple support groups I

had four glorious years of balanced healthy eating, a comparable steady, acceptable weight with no cravings and such joy in my heart.

Could I maintain nirvana? No, because I got cocky and let myself forget **the patterns**. When there are stresses from major transitions in my life, particularly when accompanied by change in environment, my appetite takes charge of my life. In June, 1995, polio dictated my early retirement from a 36 year career. Immediately thereafter I traveled for a month in another country, a trip which ended with separation from my brother and his family. Then for six months my weight soared as I satisfied all of my cravings. On December 28, 1995 I ate a half gallon of ice cream at one sitting and a bag of chocolate kisses. But today after any slip I know what I have to do to regain the equilibrium I so greatly value and enjoy. After four months of hard work I was back on the eating plan which works for me, at a lower weight than I was before retirement, grateful for the resources I have today in facing what I consider to be a lifetime challenge.

I give you this story, encouraging you to tell your own, because it will tell you what you need to know about you, food and polio to enable you to relearn eating. Take your time to document the genetics of your eating behavior, what you learned about food growing up, the profile of your lifetime weight records and significant events that connect eating with your polio experience. You will need to think about your ancestry. Look at family pictures, your relatives and you at different times in your life. What are the strongest and earliest influences on your eating habits; those which help you be a healthy eater as well as those which cause problems for you? What have been your eating patterns over time?

Simultaneously you can do a current food journal for a month, recording what and how you eat today. Be very specific, noting when, how much, where and what you consume during waking hours. Some people learn even more from recording the feelings they are having and the events which have occurred whenever they overeat. Think about what today's eating habits have to do with those of the past.

You will need time to think through the facts and themes of your story, deciding what food attitudes, feelings, and habits need to be challenged and reworked. Which will be the most difficult to change? I have gone back to my history many times over the past five years as my memory retrieves more old information to plug in, to see how it might reinforce, or clarify, or change my understanding of my eating, polio life. Hopefully, now you are beginning to see that weight management is a process which is a very interesting, exciting and important part of who you are, how you live and who you want to be.

Some polio women are successful weight managers because of what they learned, early on, about their bodies. They may have understood, also, the purposes of food. After polio recovery they accepted that their bodies were not like everyone else's; therefore, they couldn't eat like others. Consciously or unconsciously they knew that lower energy demands would require less fuel.

Today everyone can be knowledgeable about healthy eating. Magazines continuously feature articles, TV shows on food abound, libraries are full of books, foods in stores are labeled. Nutritional information is becoming part of our culture. Most of the polio women I interviewed are aware that fats, cholesterol and sugars are red flags for us and try to avoid them. But some were less clear about what we **do** need to eat and in what quantities.

"How can I lose weight and still stay within the parameters of good nutrition, eating only the 1200-1400 calories which I would need for a weight loss?"

To answer this complex question for myself I began with another question. "What do I want my food to do for me?" Nutrition textbooks told me that I want food to support my life systems, i.e. the chemical processing plant I call my body. And I also want it to give me the energy I need to do things. (4,p.7)

I now understand that the process called metabolism is the conversion of food to energy in my cells. Food is broken down into simple components and absorbed into the blood stream; then distributed to the cells of my body. This happens through complex chemical reactions. Eventually those components combine with oxygen (burning) to release heat and energy.

My food Bible, The Wellness Encyclopedia, tells me that I need in my diet protein, fat and carbohydrates to provide energy and to help maintain and repair my body. Vitamins help regulate the chemical processes that take place. Minerals play a role in body maintenance, the formation of new tissue, bones and teeth. Water supports chemical reactions, circulates the blood, removes waste and regulates temperature. (1,p.12) **We need them all.**

I have learned that food is good, not because it tastes good, but because the food processing function of my body is a miracle which makes me a healthy, functioning person. Food is only a problem when I want it to serve purposes it wasn't intended for - like making me feel happy, or solving my problems or compensating for polio losses. And food was a problem for me when I didn't take the time to find out how my body uses food and what it needs to function.

Now it feels good to follow the recommendation "that over half of the energy content of the diet should consist of carbohydrates." And because of the warning that, "if

you eat more than required for immediate storage and energy use, it becomes fat", I try not to exceed limits. (5Vol.1,p.673) I have learned that "simple carbohydrates (glucose) give you a quick energy lift and then let you down." But that "complex carbohydrates (nonsugars) are digested more slowly and are absorbed over a longer time resulting as more in energy stores and less as fat." (Ibid.) I enjoy eating my grains, legumes, salads, vegetables and potatoes knowing that my body is storing that energy and that these foods will sustain me over a longer period of time while providing me with so many of the vitamins and minerals I need.

I also restrict my fat consumption to less than a fifth of my dietary intake. "Even though fat provides pure energy" I have learned that "fat in the system can interfere with the delivery of oxygen to tissues, causing fatigue as well as heart problems and stroke." (Ibid.) The last thing my polio body needs is another source of fatigue. "However, some fat is beneficial." Charlotte Gollobin, who has written about Nutrition for Polio Survivors tells us that "Fish contains oils that help lower triglycerides and prevent platelets from clumping, thereby lowering the risk of heart disease and atherosclerosis. Although olive oil doesn't lower cholesterol levels, it improves the ratio between high and low density lipoproteins and total cholesterol; thus lowering the risk for heart disease." (6,p.14) It is important to eat with the goal of prevention. We do not need other health complications in our polio lives.

I also pay attention to the warnings about sugar and exclude it from my diet. "The body prefers simple carbohydrates (sugar) for energy because it is designed to burn glucose, not fat or protein. Beware, sugars can be addictive to some people." (7,p.96) Polio surgery taught me this lesson, firsthand. When I was in the hospital five years ago, I was put on a glucose drip immediately following the procedure. As soon as I was alert enough to recognize my body's messages, I had a profound craving for ice cream and consumed a pint. For two weeks thereafter I could not say "no" to sweets. As soon as I was mobile in a wheelchair I rolled to the ice cream and candy machines in the canteen. Finally on returning home I was able to clean my body of the sugar craving. Unable to leave the house for two months, I could not get to the store for sweets.

My nutrition text also informs me that there are no storage places in my body for protein. "There is a daily loss of nitrogen which must be replaced. Eating protein gives us long lasting energy." (5,Vol.1p.673) Doctors at Mt. Sinai Hospital warn that "the importance of adequate protein cannot be overemphasized" particularly for polio people. Lean body mass is lost in paralyzed limbs. And lean body mass is always lost with fat in dieting. Therefore, polio women losing weight must have adequate protein. These same doctors remind us that "excess weight puts a strain on muscles and joints, particularly in the hips and legs, back and feet." (2,p.280) So we don't want to eat **excess** protein either because the end result can be painful arthritis due to weight load on the joints.

I found that several doctors writing on the subject of Chronic Fatigue Syndrome have useful dietary recommendations for polio women. "A non fatiguing diet must be low in calories and adequate in carbohydrates forcing the body to burn a little fat each day; but

not protein." (7,p.96) This doctor cautions me that eating a large carbohydrate meal can give me a surge of energy and then make me sleepy. So my big carbohydrate lunches are scheduled for days when I can rest briefly but blissfully in the early afternoon.

To summarize we need a high fiber, low sugar, low fat, adequate carbohydrate and protein diet which will give us energy and fill us up from one meal to the next. Which brings us to the polio women's questions about quantity:

"How can I stay with dieting? I have to go below 1000 calories per day to really lose and I find it hard to stay at that level for very long."

"Should you count calories? I only count fats."

Whether losing or maintaining weight all people need to find a way to monitor intake; both the quantity and nutritional composition of their food. You can use any system that works for you. For me to be successful I have to measure portions, count calories, monitor food groups, and keep track of nutritional content. The Wellness Encyclopedia is a treasure of information on the nutritional and caloric content of all the basic foods, by groups. Attractive illustrations identify the foods. Cooking/preparation instructions help me maintain the optimum nutritional characteristics of the foods I eat.

Another tool for monitoring the foods you eat daily, is available to computer users in the form of software programs. I use a program called Diet Expert, published by Expert Software Inc. (1994) which allows me to log in the quantities and types of food I am eating for each meal. Extensive data banks provide me with the nutritional information required to determine if my daily plan is balanced. Summaries and charts warn me about excesses and deficiencies of important nutrients. An exercise component allows me to determine if I am burning enough calories to reach my desired goals. The software cuts down recording and computing time to 15 minutes daily. Some people work better just with food groups and portions. I like knowing exactly what I am eating, what it is doing for me or to me and the absolute limits I need to put on portions.

How much is enough, i.e. nutritionally adequate? Most medical sources I have investigated recommend that a polio woman not go below 1200 calories daily (although there is a bottom range reported, between 1000 and 1300). A dietitian at a rehab hospital tells me that "less than 1200 calories may make it difficult to meet nutritional standards." Dr. Bell, in his book Curing Fatigue, says "eating less than 1000-1200 calories per day will leave you malnourished due to lack of protein, calories and essential fat." (8,p.162) The positive side of the 1200 calories limit is that such a regimen "can be followed for months without specific supplements. However people with this low calorie intake should watch for deficiencies in iron, vitamin B6 and Zinc. Anything below 1100 must be supplemented" (with vitamins and minerals). (5,Vol2p.997)

Don't jeopardize your health with poor nutrition. Pay attention to frequency of colds, sleeping patterns, energy level, depression whenever you are reducing your caloric intake, consulting with professionals if you note changes.

Those of you who, in desperation to lose weight, are tempted to try starvation diets should know that "fasting ends up in weakness, lightheadedness, irritability, hunger and fatigue. The body reduces the metabolic rate which slows down weight loss." (7,p. 107) This regulatory mechanism of the metabolism, designed to keep us alive, is one of several reasons why it is difficult to lose weight. The lower we go the harder it is to lose. (5,Vol.1p.783)

Another problem with dieting, i.e. eating less than 1200 calories daily, was posed by the respondent's question about how to stay with the regimen. Of all those on diets only 5% maintain a weight loss beyond the first year (2,p.276) This reason is put forward by Dr. Atkinson, "I think fatigue caused by diets is one of the major reasons women find it so hard to stick to them. They lose their stamina...as their energy flags and finally give in to the body's urgent clamoring for food." (7,p.93)

Dr. Spiller, a strong advocate of Middle Eastern dietary habits, suggests a better way to "stay the course" with weight reduction. "Association with diets and dieting is negative; tied to sickness and hospitals, restrictive diets for weight loss and other medical reasons." (9,p.6) He says that many diets are too complicated with too many rules. And finally that they lack joy. He recommends that we "cherish the simple ancient foods of the land; savor their fragrance; enjoy the flavor and aroma of herbs and spices; learn to appreciate real, whole foods as part of a joyful meal; make the path to better health satisfying and pleasant... We need to love our way of eating" not to see it as a process of denial.(9,p.1)

"What are the nutritional needs of polio people?"

Frederick M. Maynard, M.D. and Carolyn Hoffman, M.S., R.D. investigated this issue through A Pilot Program of Nutrition Education and Exercise for the Polio Survivor. The only study of its kind (Dr. Maynard's literature search revealed that "no information on nutritional intake or interventions among people with a history of polio was found..."), this project demonstrated that a combined program of nutrition education and aquatic exercise helped eleven polio subjects to lose weight and either maintain the loss or continue to lose over 24 months. (10,p.70)

Dr. Maynard tells us that nutrition is important to polio women for these reasons: 1) obesity...contributes to the development of disabling musculoskeletal pain problems in the back and lower limbs as well as aggravate easy fatigueability and the experience of weakness in leg muscles used for walking, 2) osteoporosis in paralyzed lower limbs may be accelerated by poor nutrition and 3) survivors who develop iron deficiency anemia could be expected to develop severe fatigue that is perhaps even greater than what would occur in a person without neuromuscular impairment.(Ibid)

The nutrition education component of the study consists of 16 weeks of a one hour seminar led by a dietitian/health educator. The curriculum was built around The New American Diet, published in paperback by Simon and Schuster, an excellent low-fat, family weight management plan. "Weekly sessions focused on self-appraisal of current food intake, optimal protein and calcium intake, fat/cholesterol, fiber 'sense', sodium considerations, and facts and fallacies." (10,p.72)

The curriculum directly addresses our problems. "Often people with the late effects of polio are faced with having to conserve energy ('conserve it to preserve it') in order to be most healthy. This necessary change in lifestyle can create new weight problems." (11,p.75) The authors assume that for weight loss most of us have caloric needs which do not exceed 1200 calories daily. They encourage a balanced diet with particular attention to adequate intake of vitamins C, D and E, calcium and fiber. Like anything else vitamin use can be abused. Megadoses should never be self prescribed.

In my own food regimen I supplement two daily glasses of low fat milk with 1200 mg. of calcium fortified with vitamin D. Most of the fruits and vegetables I eat, broccoli, cauliflower, brussel sprouts, sweet peppers, grapefruit and oranges are rich in vitamin C. It is more difficult to find adequate natural sources of vitamin E, although vegetables like asparagus, spinach, tomatoes and brussel sprouts do contain that vitamin, as does the wheat germ in my bowl of wheatena. Poultry and some fish provide a limited source. Many of the grains, fruits and some vegetables are good sources of dietary fiber.

We can find encouragement in the fact that weight management problems of the polio person have been considered to be a worthy topic of investigation by a clinical team. All of us can be more proactive by discussing this curricular project with those local health professionals who are currently responsible for our polio care. Perhaps we can inspire the creation of outpatient clinic programs which will monitor our ongoing nutrition education and progress in reaching our goals. Seeking support from medical professionals is something which, by now, we do well. My most important first step in finding out what and how much I should eat was into the office of a nutrition specialist, a dietitian.

Significantly the New American Diet book, used in the Maynard-Hoffman study, is also on the Good Nutrition Reading List of the National Center for Nutrition and Dietetics of the American Dietetic Association. This useful, informative meal planning guide suggests ways to get "the whole family involved" in changing basic eating patterns for a lifetime; first through substitution of healthier options for butter, whole milk, lard, egg yolks and fatty meats; second by introducing new recipes which use less meat, cheese, fats, salt, etc. and finally by adopting a food plan which consists entirely of nutritional foods, avoiding those which are unhealthy. (12,p.36) This is a transitional program which takes into account individual differences.

To the polio women who, like those I interviewed, are asking: *"How do I make good solid meals?" "Where can I find an easy healthy diet that tastes good and my family will eat?" "Is there a good general diet that doesn't require extra work and my husband can use too?"* part of the answer is found at the bookstore with the purchase of The New American Diet, the Wellness Encyclopedia and, if you like, another source recommended by Charlotte Gollobin, Jane Brody's Nutrition Book (13), published in paper by Bantam Books.

The good news from the psychologist is that we **can** learn new eating behaviors. "Food preferences can be modified by experience, both nutritional experience and the social consequences of food consumption." (3,p.101) She points out that we tend to eat like the important other people around us so choose your mealtime company carefully, and do engage your entire family in the goal of healthy eating. Experimental studies have shown that preferences and aversions to food have to do with preparation time, availability and cost. We choose what we can get more easily, more readily. This is a good argument for keeping snack food out of the house. The psychologists warn us that the longer we have to wait for our food the more impulsive our eating behavior becomes. (3,p.121) So eat on a consistent schedule knowing that "a precommitment to a goal helps override impulsivity." Through the work of psychologists we have available to us important principles on which to base new ways of eating.

Those people in the world who are successful losers and weight managers have been studied by two psychologists who have established the National Weight Control Registry. (14) People belonging to this group "have lost 30 pounds or more and kept them off for at least a year." The doctors conducting the program compiled this list of their characteristics.

- They want to do it (i.e. lose or maintain weight) **for themselves.**
- They set realistic goals ("genes set the lower and upper limits of your weight but it's lifestyle that moves you up or down within that range.")
- They don't deprive themselves ("they adopt a sensible eating plan they are content to stay on for the rest of their lives.")
- They are willing to cut out most fat.
- They are active.
- They always keep track of their weight, their portions and their daily exercise.
- They are organizing, problem solving types.
- They have come to terms with lifetime acceptance of managed eating and are at peace with it.

This chapter has focused on nutritional information in books, and programs which begin to respond to the questions of the overweight woman with polio. It establishes the fact that we have different nutritional needs but that we can still eat within reasonable limits to lose and/or maintain our weight, as some of our successful polio sisters have found. Professionals who have studied nutrition and psychologists can provide us with knowledge which we can use to change our understanding of and approach to eating.

Instead of one more unsuccessful, demoralizing and unsatisfying diet, we can learn to create and enjoy meals which provide the nutrition required to sustain our polio bodies.

Other important weight management questions which come from my polio survey participants have to do with eating behaviors and strategies for learning new eating patterns. In the next chapter you will meet a woman with polio who, because she loves to cook, found her own solutions and wrote about them.

The most basic question asked me by one of the frustrated dieters, who was struggling with her food consumption was:

"What specifically do I have to do!"

This chapter is about what you can do to make the struggle simpler in the areas of cooking, meal planning and shopping/storage. But first, go call the Consumer Nutrition hotline of The American Dietetic Association at 1-800-366-1655 to get a list of registered dietitians in your area. Make appointments until you find someone with whom you can work. As you approach those help sessions, open your mind to changing your most rigidly held beliefs about food, what you think you need and what you are willing to try. If your starting point is "I can't....because..." you won't get very far. Sometimes our polio-developed stubbornness, which gets us over many hurdles, can become an obstacle to change.

But our experience with polio also has fashioned our characters and personalities in wonderful ways which we can use to our advantage. In this chapter I will suggest that you use these, your polio competencies, to manage your food life in new ways. Those competencies, planning, patience, coping, compromise and commitment, have made you an adaptable person who, with great spirit and purpose, has been able to achieve some pretty amazing accomplishments.

Cooking

"I love to cook and eat. Cooking makes me hungry."

"I don't have the energy to cook and clean up."

Fifteen years ago a Canadian woman who liked to cook, Mary E. Blakeslee, wrote about these dilemmas in a recipe book which she called The Wheelchair Gourmet, A Cookbook for the Disabled. Mary approached the physical challenge of cooking with good problem solving strategies; she defined her limits and found alternatives.

Since being forced into a permanent sitting position some years ago as a result of a losing bout with polio....I began to search for tricks to beat the handicap. First I began to discriminate between what could and could not be handled with a physical handicap. Second I woke up to the potential of small appliances. (15.Pref.)

Thus freeing herself from the obligation "of rolling pastry and kneading dough" she created recipes which capitalized on the conveniences of the blender, meat grinder, mixer, food processor, bread maker, electric fry pan, crockpot and microwave. Today she has access to many distributors of small gadgets for people with disabilities which simplify, modify and make even safer the activities involved with cooking.

Cooking can be an important part of the process of nurturing ourselves and others; we don't need to give it up. In fact, it can be important exercise for some women with polio. If you enjoy cooking you want to think of it as an opportunity to do something good and special, using your time and energy to provide you and your family with nutritious and tasty meals. The good polio cook, according to Mary Blakeslee, uses recipes that fit within the nutritional guidelines discussed in the last chapter.

You will find that practically none of my recipes contain white sugar, or its equally evil companion white flour...Sugar raises your energy level - sure it does - but the high lasts about as long as the euphoria from a cigarette and like that same cigarette, sends you sinking to the depths in ten minutes. (15,p.1)

You can tell from her recommendations that as a cook she was thinking about what foods can do to and for her body. She created recipes using ingredients which would help her manage her weight. One advantage for the weight watching cook is that she works with natural foods which are usually better than manufacturer processed products; more nutritious, have less calories and no artificial ingredients, and are better tasting. If you have cooked it, you can feel confident in knowing exactly what you are eating. And Mary's recipes are nutritionally sound for those who are worried about the health issues related to decreasing mobility.

People with the kind of physical handicap that puts them in a wheelchair are especially in need of foods that are going to build and repair body tissue and keep energy levels at an even high - namely proteins. (15,p.2)

She understands that proper management and cooking of foods can protect us against future health problems.

You will also find that I either don't cook or barely warm the vegetables in my recipes. Not only does overcooking siphon off the nutrients but it also removes one of the great benefits of raw vegetables - the scrub brush effect. Anyone who sits a lot - and who sits more than a wheelchair rider - becomes an automatic candidate for the joys of Preparation H. The best way I have found to beat the problem is to eat a lot of raw vegetables every day and drink water by the gallon." (15,p.1)

And since all cooks know that the ultimate criteria for success is taste as well as nutrition, she recommends:

In the interest of keeping blood pressure at a reasonable level, try to acquire a taste for the natural flavor of food. If you want to add a touch of class, get on a first name basis with basil, rosemary, sage and thyme. (Ibid)

Women who enjoy cooking need to become good recipe critics, selecting those dishes that either can be measured, packaged and frozen or that won't create leftovers. They need to pay attention to Mary's warning about recipes which depend on white flour and sugar, adding to that list: cheese, butter/shortening/margarine, peanut oil, chocolate, whole milk or cream. You will choose instead recipes that use natural foods which aren't appealing to snack on, discouraging you from eating half of the meal while cooking it.

And you will do your serious cooking immediately following a meal, when you are least hungry.

Like Mary you can learn to be a creative cook, making your own recipe file with recipes which fit your polio weight management needs. Use but don't depend on recipe books written by the walking world, for the jogging eater.

If you don't like to cook or prefer to expend your limited energy in other ways you have the advantage of not spending much time around food, tempted by the sights and smells of the kitchen. Your challenge is to plan nutritious meals which require less preparation, but which are satisfying until the next meal. Mary's recommendation about exploiting the technology of small appliances is a good one for the noncook as well - it's okay to make three meals in a crockpot and freeze the second and third portions. But of all the skills and strategies I, a noncook, have learned by far the most useful is to have, for every meal and for every day of my life, a meal plan.

Meal Planning

"How do I deal with the issue of choices?"

"How do I resist my grandchild's Easter egg in the cabinet?"

The answers to these core questions are found in the meal plan. It is important to understand that meal planning is not dieting. Everyone could benefit from doing it. In fact, there is no way to have balanced, nutritious meals without meal planning. Not a process of depriving yourself, meal plans provide your body with what it needs and only what it needs to run efficiently.

As polio people we are master planners. We don't move without thinking ahead and asking questions. Why do I need to move? Is it really necessary? What is the shortest distance? Where are the least obstacles? Are there places to rest along the way? Can I accomplish two or three tasks with this one move?

It is equally important to approach feeding with planning questions. Am I hungry? Is what I am eating filling my daily needs for protein, carbohydrates, fats, vitamins, minerals? What did I eat yesterday? Will I be eating out this evening? What portions of food do I need today to equal my allotted intake? How active will I be?

And for polio list makers (I'm sure you are one) nothing could be easier than to record the answers to those questions in the form of a meal plan, a list of the foods you will consume during any given day. Here are the steps:

- meal planning is done ahead of time (I do it weekly but some prefer to do it the night before each day)
- meal planning is always done in writing (like a contract)

- the meal plan indicates when you will eat each food
- the meal plan includes everything you are going to eat for that day and the quantities
- the meal plan can be easily organized on index cards (don't throw them away; they can be recycled in future weeks/months)
- on the back of the card you will total your daily calories, and summarize vitamin, mineral and food group information as you wish

Your meal plan goal is to eat food that is filling, nutritious, takes time to digest and provides maximum energy with minimum calories/cholesterol. You commit yourself to eating only what is written on the card, in the quantities recorded, at the time stated. You do not raid the cabinet for the Easter egg because it is not in your meal plan. You can put it into your meal plan, if you wish, but you will probably be hungry and worn out that day because it will use up so many calories and provide such short term energy.

The meal plan freed this polio person from an intolerable burden, too heavy for my body and soul to carry. I no longer had to think about food all day and I lost weight. Now I don't make decisions about food when I am hungry. And I am confident that with each mouthful I am getting what I need to be healthy. The meal plan sets limits for me, which I could never do, but it also gives me autonomy (I am making the decisions) and appropriate choices.

In addition to being able to select from a range of food categories and varieties you will be choosing when to eat. The first and most important conversation I ever had with my dietitian had to do with this choice. She explained to me that the stomach empties every four hours. Her recommendation was to avoid going beyond 4-1/2 to 5 hours between meals, except at night. I was overjoyed to discover that if I ate at 8 AM, 1 PM, 6 PM and 10 PM I would never again feel hunger pains. You need to plan your best time table around your own personal hunger cycle; you may prefer lots of little meals. Whatever you choose should fit easily into your sleep schedule and daily life so that you can stick with it, reassuring your body of a new energy supply on a dependable basis.

How we eat provides lots of choices. The hows of eating are so important because they help make a meal gratifying and satisfying without those unhealthy foods which were once the source of our eating pleasure. We have choices about where we eat; dining room, breakfast room, kitchen, family room, at a table, in bed, picnic style on the floor. My favorite meals are served on my screened porch in the summertime.

We can choose to eat quickly and get on to other interests (but not too fast to miss the nutritional and digestive rewards of chewing) or slowly. I have an audio tape through which a healer teaches me how to experience eating as a spiritual act in which one honors the body as the temple of the soul. He chews one mouthful of rice over a hundred times, savoring the flavor and focusing on the good he is doing for mind, spirit and flesh by eating in a spiritual way.

We choose between serving food hot or cold; knowing that cold or room temperature finger food often requires less preparation effort but aware that heated food releases smells and flavor, sometimes making the food more satisfying.

For me meal presentation is important. I enjoy using a cloth napkin (though I choose not to use energy laundering table cloths and mats) and put fresh flowers or a plant on the table if available. I always eat breakfast by candlelight - just for fun. You can dress up the meal with fine plates and silverware if that's your style. I have found that using smaller plates helps me feel like I'm eating enormous quantities. I do help myself by serving the food directly onto my plate (never into serving bowls) and if I have extras I put them away before the meal, keeping my food warm in the oven.

The ambiance can be suited to different tastes; some prefer company and conversation, some music, the TV news or a newspaper. For a rare few it is a quiet, peaceful time of reflection and restoration. Just be sure that you are making conscious decisions about these variables to maximize your pleasure. We have so many ways to please ourselves at mealtime which have nothing to do with eating dessert.

But the one choice which the meal plan limits for us has to do with why we eat. Adopting a meal plan means that I eat only to nourish my body: not because I am tired, not because I am stressed, not because I am coping with strong feelings, not because I am lonely, not because I am bored. The meal plan gives us choices, sets appropriate limits and it provides us with our shopping list.

Shopping and Storage

"I would ask to have help planning a menu that would give consideration to shopping difficulties...."

Never going to the store without my meal plan shopping list I let my polio limitations and technology help me with shopping. First I choose the store with care; I only frequent those with scooter carts. Riding takes the weight off my legs so that I can take my time and not buy impulsively, and the basket is too small to carry extras. I choose a store where fast food is not being pushed at me encouraging me to eat as I shop. I go where lots of effort is put into attractive, fresh produce displays and where food smells are not permeating the atmosphere. I find a store where I can do one stop shopping, saving energy. I avoid specialty stores: the bakery, cheese shop and gourmet retailers.

Living alone I can get by with once weekly shopping trips; the remaining six days I do not go into stores to pick up one of these, and two of those, and by the way there's a sale on that fruit which I love. I shop right after a meal, preferably breakfast when I have most energy and am not hungry. This gives me adequate time to plan my excursion, shop for and put away food without pushing myself.

While in the store I go only to the aisles where I will find the products on my list, saving time, energy and exposure to the snack aisle, the candy and ice cream aisles. I don't look at products other than those on my list. With list items I take time to read ingredients and nutrition information. I always look for sugar and flour content, knowing that any ingredient listed beyond the fifth item exists in insignificant quantity. Today we are blessed to have low fat, and sugar free foods and the packaging information. It is up to us to take advantage of those options and that knowledge.

Let your polio limitations help you to set shopping limits; you will not need to lift, carry or put away what you don't buy. And I have found that my bags of produce are significantly less heavy than bags of soft drinks, cake mixes and frozen dinners. I avoid getting my priorities mixed up; trying to save money by always buying in bulk or because something is on sale. I will end up with the bulk on my hips, having extra food on hand which I might feel obligated to eat before it goes bad. I save money instead by not buying sweets and snacks. If I want an occasional splurge I spend on mild bell peppers (expensive but high in nutrients and delicious), out of season fruits or seafood.

As soon as I get home I wash and wrap my greens in tea towels and plastic bags so that they will stay fresh for the week. If I have to buy food that is risky for me (to go into the dish for the church potluck) I store it up high and out of sight until I cook it. Safe storage also includes weighing and packaging my 4 oz. portions of poultry or seafood which go into the freezing compartment. Freezing for the microwave is a blessing. When I worked full time I prepared all of my mid-day and evening meals in bulk and then froze measured quantities. What I saved in cooking and clean up energy was significant.

If you are measuring, cooking and shopping for your specific meal plans you shouldn't have leftovers. You are buying exactly what you need. Leftovers are a warning to check your plans. You have surely found that keeping dabs of food in the refrigerator is an invitation to snacking. I encourage you to challenge your most basic beliefs about thrift, survival and conservation by throwing extras into the trash; those of us who are occasional trash raiders need to remove the trash immediately to the outside cans. Practice trashing gift boxes of chocolates. Doing so gave me a marvelous feeling of power. Or give away such "gifts" but, in doing so, never sabotage others who have trouble with food.

"How when I am going out, to adopt a mind set where I am still thinking 'eat healthy'?"

Entertaining and eating out present such problems to the women who were interviewed that I want to pass on some tips I have appreciated. When I entertain I serve my friends the healthy food I eat. Most of them are grateful! Others save me time and energy by not accepting another meal time invitation.

Many restaurants today are anxious to accommodate our eating and cooking requirements. They want our business. Sometimes I call ahead to inquire about the menu,

to find out if they have "healthy entrees" and "heart smart" cooking options. I insist on time with the waiter, asking questions and being specific about what I want. I have known women who are very serious about managing weight who take measuring cups, spoons and scales with them to the restaurant. They enjoy being out more if they can measure quantities. If that makes you feel conspicuous you can use the size of your fist to visualize a one cup portion.

Our reasons for eating out are important. I don't go out to eat food any more. I go to be with friends, or to get a change of atmosphere, or to be served and not have to clean up. I use eating out as an opportunity to enjoy dishes which are complicated to prepare or are new, interesting combinations which I don't have energy to fix at home. I try to order first so that I am not influenced by others' choices. I order a la carte and I stop eating when I am full. Remember that the doggie bag is only for those who have dogs.

Many of the interviewed women with polio reported that the hardest time to manage their food is the evening when they are watching TV. To avoid this problem I have an evening snack (9:30-10:00) built into my meal plan; a piece of fruit. Cereal or yogurt are good options. If I am watching the TV I use the mute button to cancel out the 25 food ads which confront me over a two hour stretch of programming. I read or sew until the program resumes. I don't read women's magazines at night for the same reason, food ads.

For me these strategies aren't gimmicks. They are an integral part of the new way I think about and interact with food. I learned them, albeit late in life, because I needed all the help I could get to change years of thoughtless, impulsive food behavior. I also draw heavily on what I call our polio competencies. You can use them, too, to help yourself. They can serve you well in becoming a proficient weight manager. Use those **planning** skills to organize your food around nutritional choices and a comfortable schedule; a workable meal plan.

How many hours have you survived waiting in medical settings? How much time do you have to give your body to recover after surgery? Call upon the **patience** you have developed to adopt a long range plan to weight management. Anticipate making incremental changes to your food plans. You have a lifetime to gradually accomplish your goals.

You have learned to **cope** through successful **compromise**. Making food choices is a process of making compromises in behalf of what you really want for your body. Food will never work as a compensation for losses; compromise can help.

As a polio woman I know that I sometimes need **crutches**. And today I am comfortable using them. I use sugar substitutes, caffeine free diet sodas, low sodium salt and decaf coffee; crutches which help me make compromises.

And at some point in your life you were able to make a life restoring **commitment** and stick to it. In spite of dire medical predictions you decided that you would become sufficiently mobile to live a productive and satisfying life. Some of us now need to make a second commitment to that mobility by meeting the challenge of managing our food.

Because movement, activity, and exercise are important factors in the weight management equation, the next two chapters will focus on what we can learn about and do about ourselves and our environment to maximize our ability to get around.

The activity history is about change, our changing polio bodies which require changes in our food habits and activity patterns. Change is difficult. Our bodies are much better at repeating past behavior, seeking stasis, than at changing. Words can help us with the difficult task of changing. Words beget ideas; ideas beget activity; activity begets change. Because of my polio mind set I find the words "mobility" and "exercise" particularly limiting.

One woman in my sample reported, *"My weight has always been up and down but I walked everywhere."* To many of us mobility means "I can walk" and walking means everything to us. The ultimate death sentence many of our parents heard was "she may never walk again." It is easy for us to now assume that if we can't walk we will lose our mobility and therefore gain weight.

Not true on two counts. Because of the wonder of scooters and electric wheelchairs we can stay mobile, i.e. be able to get around, as long as we want. Secondly mobility really means "being able to move." We need to remind ourselves that our bodies can move in hundreds of ways other than walking. I particularly have to remember this, having spent most of my life trying to live up to the demands of my last name (no, it is not a pen name!) I often wonder how my life would have changed if my father had been Mr. Rider? To avoid the limiting polio concept of the word mobility I will talk instead, as the dancers do, about movement.

"I am active with swimming, water exercise, piano lessons, Sunday excursions, a full time job. I don't get enough exercise."

To this respondent the word "exercise" means the health club concept marketed today as the panacea for losing weight. To others exercise refers to our early experiences with a physical therapist (called treatments in those days). I prefer the word "activity" which extends the possibilities for those who are restricted from physical exercise or walking, understanding that many readers can still do both.

"My exercise is taking care of myself. I think I should exercise. I try to swim some in the summer but mostly I just lie on the float in the pool."

As this respondent suggests, taking care of oneself is being active, expending energy. But hear the guilt she feels about her pool activity. The fact that she leaves her house, goes to the pool, changes her clothes, gets in the pool and then relaxes her muscles so that she can reverse the process is overlooked because she has swimming expectations which she is unable to meet, which feels to her like failure.

Expectations can get us in trouble, as I learned when I looked back at my lifetime experience with decreasing movement and the activity decisions I made along the way. Like the telling of your food story, understanding your activity history is enlightening and

can be life changing. Because weight management depends on the food intake = energy expended equation, clarity about your activity patterns will guide you in meal planning and adjusting your meal plans over time. But even more important, the history aids us in developing a personal philosophy and practice of movement and rest which can maximize our daily energy output. But first, the history. Mine is told in two chapters: 1. Paralysis; 2. The Awakening.

Paralysis Although mother loved to describe me as an inactive ("lazy") baby who wouldn't turn over by myself until I was nine months old (probably because I was fat), once I was walking I became an average weight, normally active child. I have video tapes of me at age two, throwing myself into a pool with enormous glee, to any adult who would catch me. My love of running led to my first serious injury when I raced a friend down our hill to the house for a popsicle, stopping myself by placing my arm through a window pane. I learned to fear doctors as the pediatrician gave me twelve stitches on the living room sofa without anesthetic. During that disasterous year, 1944, the polio virus invaded my body and I never ran again. In fact, I walked with effort from that time on.

Mother and I were going to walk uptown for a new pair of school shoes but I felt too sick to go. That night I collapsed on the bedroom floor. Six months in the crib on the hospital ward were followed by learning to walk again with assistance from high shoes, lifts and wedges, physical therapy and crutches. This is a familiar story to anyone who has had polio.

As a survivor of a devastating illness, like some of you, I was able to deceive myself by believing, "I had polio. It's over. From now on it won't have any impact on my life." Through treatments and the miracle of neuronal branching I reinforced this belief by shedding my crutches within two years. But my insistence on participating in physical education classes in school was a frustrating exercise in failure. I tried to learn tennis, basketball, field hockey, gymnastics and I did ride horseback until falling off, breaking my weaker leg in 1951. By this time I gave up hopes of being on sports teams. I didn't have the power, speed or stamina to compete with energetic teenagers. I tried to compensate by being team manager (eating the snacks I prepared for the athletes.) Since no one attended to environmental considerations in those days I lived in a house and went to a school each with three flights of stairs, replete with steps with no railings. These parental decisions were important in establishing my core belief that there were no limits for me.

However, Mother did try to intervene as I set my heart on attending a college which was guaranteed to make my life more difficult and restrict my mobility: a 500 acre campus of four story buildings, connected at great distances by pathways which were covered with ice and snow for four of the nine months in session. Unfortunately I prevailed. All of the natural and man-made barriers severely limited my participation in campus life. I was doing minimal housework, caring for my single room; even dinner was served. My primary activity was sedentary study. I can still feel the pain and fatigue as I walked along pushing my bicycle, books and extra weight up the hills to class and the

dorm. I could only ride downhill. This was my daily exercise. The rest of the time I stayed in my room, smoked, snacked and studied.

When I joined the working world did I ever once think about transportation, climate, accessibility of residence and workplace? Even in those days there were choices. No, I followed my friends to New York City where I spent three years walking to and from work, the grocery store, the cleaners, lifting and carrying, climbing and pushing. When I began to fall down in the midst of city traffic I was forced to accept the unthinkable and purchase a pair of crutches. Even with those aids when I got home at night I crashed and avoided many of the activities which my roommates enjoyed. I was not getting appropriate, manageable exercise and, except when I was dieting, I gained weight.

A friend who had polio, who has never experienced the weight gain spiral, told me her comparative experience. She attended a one floor, special needs school with ramps and transportation. Upon graduation she lived and worked where she could use a car which she immediately had adapted with hand controls. She chose to work in buildings with accessible parking and elevators. Once married she and her husband bought a one floor house.

In contrast I went back to study, live and work in New England a second time, after surviving the wind, ice and snow while working in Chicago. My first conscious environmental decision was to return to the more moderate climate of Philadelphia. But I chose an apartment across the street from the campus where I worked in three, three-story buildings, no elevators. And I walked all day, to and from work, upstairs and down long corridors in a supervisory job. It never occurred to me that I could look for more sedentary work in a barrier free setting.

Chapter one of my activity history concludes with ten years of moving six times, once across the country; an exhausting marathon which I couldn't run. I finally said "no more moves" preferring a commuter marriage. My final destination was a three floor house where I did all the chores, cleaning and maintenance, even acting as purchasing agent and foreman for the replacement of the house's double roof. Simultaneously I worked another supervisory job on a 40 acre campus covering six multistory buildings, only one of which had an elevator. I collapsed once again.

Driven by the fear generated by the initial experience of paralysis, I pushed myself relentlessly, beyond my limits every day. Each night and weekend my body would crash, leaving me no choice but periods of self-imposed isolation and inertia; in fact achieving the immobility which I was working so hard to escape. The resultant stress and fatigue I fed with calories I could never burn up.

The Awakening

Chapter two began in 1985, ironically with the need for a new pair of shoes. The salesman in the orthopaedic shoe store noticed my back knee condition and told me that I

needed a brace. I was horrified but my exhausted body forced my brain to believe him. Through an orthopaedic doctor who knew nothing about polio I found a bracemaker. Unlike the purchase of the crutches twenty years earlier, the brace couldn't be put aside at will; it was to become part of me. The brace made a statement about me to the rest of the world which I could no longer ignore. The period of accommodation to the brace was an awakening from the emotional paralysis which never had allowed me to accept the fact of and limitations of polio. I began to talk to people about wearing the brace, asking them how they felt about me in a brace. It was a heavy, ugly thing, and I felt tired and awkward using it. But it did prepare me for the most significant moment in my activity story; this scene in 1989.

I am sitting in my car across the street from a "home for incurables." I am having intense feelings of fear and pain because I have agreed to serve on the Board of this institution and I have to go into the place so that I can be interviewed. Forces are at war inside me: the force that wants to enter and see disabled people all around me, who need, as I do, to embrace their limitations and go on from there; and the force that wants to escape from the horror of the powerlessness which I did and which I assumed they also feared. The immediate problem is that I have just driven around the large complex and found no empty parking places except those marked with large blue and white pictures of a stickfigure in a wheelchair. Limited as I was, with brace and crutches, I had to park across the wide, busy street because up until that moment, to my mind, I wasn't disabled and I certainly wasn't handicapped. I sat in my car and laughed through my tears as I realized it was time to open myself to the possibility of becoming a "wheelie", of changing my license plates and my life.

From that moment on I set out to learn and do all that I could to facilitate my movement. I found a clinic for my polio care. I had surgery which relieved excruciating hip pain. I got two lovely, lighter plastic braces appropriately engineered to help my gait. I bought a "one-floor-for-living" house and installed a chairlift to the basement and indoor garage. I had the car adapted with hand controls and a lift for my new scooter. I even walked away from the job that was sapping my energy and muscle strength, preferring to be broke, rather than broken. Now, in retirement, before taking on volunteer activities I ask about parking, accessibility, stairs and distances.

With this growing awareness of the interaction between my body and the environment the latter seems so much less hostile. For the first time in my entire life I relish being outside, aware of and enjoying the beauty of the natural world because my body isn't shouting at me: How many more steps? When will you sit down? Why are you hurting me? When can I go home?

I knew finally that I had incorporated braces, canes and polio with my identity when I went to a weekend workshop on anger. In response to a workshop activity I drew a pictorial timeline. Before a group of thirty strangers I described my history of life events, ending with a picture of me today, in braces, with cane, looking very pleased with myself. I was! Draw your activity history if you prefer.

My history makes me aware that overtime I am losing the muscle strength and stamina that I had as a post polio child, but that accommodations can be made. It reminds me of a long period of misspent energy, now replaced by more efficient and productive use of the resources I have. It warns me that when I refuse to accept my polio limitations or prefer to ignore them, I am missing an opportunity to work with those limits to maximize my movement and thereby, my energy output.

I now have the time to get good exercise from doing my housework on a planned system; cleaning one type of room each week on a five week cycle. I now have the energy to get myself to the pool most days of the week to alternate moderate swimming with stretching exercises for thirty minutes. I have the freedom to plan my days around interests which get me out of the house and with other people, and times to be home to prepare and eat my nutritious meals, and rest my muscles. I feel truly mobile for the first time in my life even though I walk far less with much more assistance. The rhythms of my body are in balance with the demands of my existence, and the features of my surroundings.

The women who I know, who had polio but haven't experienced weight management problems, may have more cooperative genes and metabolisms. But they also had:

- greater movement issues because of more profound lower body weakness;
- therefore they had to recognize and deal with their polio limitations from the time that they left the hospital;
- they are more aggressively disabled (i.e. find power in their disability);
- they have found a relatively comfortable perspective on living, most frequently expressed through humor;
- and they learned early how to make the environment work for them, instead of overworking their legs to overcome environmental obstacles, expending energy on unrealistic expectations.

Today they have enormous energy which is channeled into activities and interests which they **can** do. Sure they have days of fatigue if they do too much but on the whole their daily activities are well balanced within limits which they can handle. For them fuel in = energy output.

As you have read, the activity history relates the movements you have been required to perform over a lifetime related to education, employment and parenthood; activities required for housekeeping, self care, life management; activities engaged in for recreation and physical exercise; and activity required for getting around, i.e. walking, driving, public transportation etc. In telling your activity history you will be thinking about all of these aspects of your life and answering these kinds of questions:

1. What movement patterns have you established over the years? What decisions of yours (or others) have facilitated or restricted that movement?
2. How aware are you of environmental factors in maximizing your movement? Do

the settings in which you have chosen to live, work and play control you or are you in charge of your movement?

3. What expectations do you have of your polio body? Do you pay attention to its messengers, pain and fatigue?
4. How does your food story relate to your activity history? Has less activity always corresponded with weight gains or are there other variables which have an impact?
5. What drives your activity thoughts and decisions? Is it fear of returning paralysis and ultimate immobility or confidence that your polio experience has taught you (and your polio competencies will enable you) to reach and maintain a food/activity balance?

Do an activity profile for this week. What did you do today that required you to move your body? For how long? When did you rest that body? For how long? How fatiguing was the activity? How conducive was the setting? What adjustments do you need to make for the next day? For today, did you accept and work with the limitations which your bones, muscles, joints and damaged nerves impose on you? Were you able to meet your expectations or do expectations need to be changed? Did you congratulate yourself on what you **did** accomplish?

We all know that we must eat for energy to live and we must expend energy or we will store fat. From the last chapters we know how to eat those foods which provide the most energy but are least likely to be converted to fat. From the next chapter we will learn what kinds of activities are essential to our daily well being and how to manage movement in the interest of managing our weight. We will explore how to do them in ways which will not harm but help us find the psychological equilibrium which an awkward body has never been able to provide for us.

Movement is hard work for us. Sometimes movement is accompanied by pain. Doctors in polio clinics around the country are working to alleviate movement problems for the polio person. They are doing much to help us. But we mustn't expect them to have all of the answers. Polio has puzzling after-effects. Just as doctors don't know how the brain controls our appetite for food, nor do they totally understand the sources of the fatigue we experience or the causes of overuse or disuse of muscles. (16, pp.170,153) Because medical investigators have come up with conflicting reports on the benefits of exercise, many polio women are confused, hesitant and in some cases afraid to engage in any consistent exercise program. But for those of us who are too heavy, expending energy is what we must strive to do in every safe and possible way.

Activity is a normal bodily process, like eating, with important purposes relevant to maintaining the health of the organism. In addition to helping weight management, activity is essential to maintaining a healthy heart, regulating cholesterol levels, and controlling blood pressure. It increases calcium deposit in bone and produces chemicals in the brain which help us feel good. (4, pp.307-9) Activity levels placed on a continuum range from the body at rest, when energy is still expended involuntarily to maintain body systems, to extreme exertion during sustained aerobic exercise. We need the advice of our polio doctors to select from that range the activities best suited to our polio conditions.

Given reliable polio advice about our personal limits and capabilities, we still have a job to do for ourselves. The job is complex; worthy of explanation. We need to 1) listen to our bodies; 2) understand the components of activity and rest; 3) explore exercise; 4) and practice energy conservation.

For a long time I thought that "listening to my body" was an alarm system only for pain management. Not so. Because of my weight issues and polio, when the red light on my brain panel flashes the warning "low energy!", I have to first make sure that I'm understanding the message. Could it mean that I'm hungry? If so, I should anticipate eating my next planned meal. Does it mean that I'm tired? If so I should certainly sleep. Does it mean that I'm feeling polio fatigue? In that case I need to rest. If it means that I'm overworking certain muscle groups, then I should relax them. I might also misinterpret feelings of apathy or inertia, which are signs of emotional distress. Or be experiencing emotional overload from stress, requiring a lifestyle modification, or meditation, or a good massage. The point is that my body often gives me a very generalized alarm signal which could alert me to a problem in any number of rooms.

Notice that the response for each energy loss message is quite different. What I choose to do has implications for my body. If I lie down and fall asleep, not because I'm tired but because I'm feeling muscle weakness in my arms and legs, I may risk upsetting my sleep cycle. If it's mid-afternoon and I'm feeling polio fatigue instead of hunger weakness, eating will give me a gain in pounds as well as a surge of energy, encouraging me to continue to abuse tired muscles. Instead what I need is a 15 minute rest.

Hopefully, by careful listening, discrimination and appropriate action my alarm system doesn't have to register pain since I am responding to the correct need before it becomes exacerbated. As polio people we have become particularly adept at tuning out our bodies' messages. As one of the women questioned told me: *"More pain than I am aware of limits my activity."* We sometimes need hearing aids as well as crutches.

Attentive listening operates best in the framework of understanding the components of activity. Activity, like us, cannot stand alone. It needs its counterpart, rest, in order to function. Looking back at your daily activity journal you will begin to see patterns, rhythms and cycles. On good days mine is like the harmonious movements of a symphony: sleep, eat, activity/relax, rest, eat, activity/relax, rest, activity/relax, eat, activity/relax, eat, sleep. The relax periods are my intermittent muscle relaxations during activity. This is when I take inventory of all of the muscles of my body. Are they tense or relaxed? Do I feel any weakness or pain? The rest periods are 15-30 minute breaks in activity. This is when I sit in my recliner, legs up, and read, watch TV, do needlework or write letters.

What I have discovered is the interdependence of all components of the activity cycle. The disruption of one can affect all or any of the others resulting in pain, exhaustion, sleep deprivation, muscle overuse or disuse and weight management problems. The latter has to be addressed in relationship to all of the others. The Chronic Fatigue Syndrome doctors are particularly aware of this interdependence, always discussing their patients' fatigue issues in the context of activity (exercise), nutrition, rest and sleep. The important point they make is that we need activity and (probably some exercise) to balance the rhythms of our body, not necessarily to lose weight.

The issue of exercise, one smaller aspect of activity, is of great concern to overweight polio women. *"How does a person with the late effects of polio, lose weight when you can't exercise enough to even maintain the weight?"*

This question from one of the respondents, but echoed by several others, can be answered with another question. Do we need to exercise to lose or maintain weight? Exercise does help some people but it may not be essential. Doctors who have studied weight loss and exercise tell us:

- it takes a significant amount of physical effort to expend a significant number of calories
- exercise does not inhibit food intake
- some studies show no effect of exercise on weight at all
- exercise is more effective in weight maintenance than in dieting. (5, Vol2 p.998)

A recent study reported in the Journal of the American Dietetic Association supported the last conclusion. "The results suggest that dieting is associated with weight loss followed by **regain** after treatment ends, whereas exercise alone produced smaller weight losses but better maintenance." (17,p. 342) The dietitians propose a need to "reset the focus on weight loss treatment that minimizes **relapse** and its deleterious effects, such

as sense of inadequacy and metabolic alterations." (17,p.345) The study suggests that the exercisers stayed with their exercise programs because they enjoyed it, while the dieters didn't enjoy what they perceived to be deprivation.

Enjoying exercise? That's a tough one for some of us, but like enjoying foods free of sugar, we can learn to do it. First we have to remove our worry about exercise. Our polio women are asking,

"Is there safe exercise for me?"

The polio doctors who address this question daily in clinical practice tell us that the key issues are overuse and pain, both of which need to be controlled. They warn, "Traditional therapy such as exercise may cause further weakness, so it must be used cautiously." (6,p. 166) This warning tells me that I need an exercise program which has been prescribed by doctors or therapists who have worked or been trained in a polio clinic setting. It doesn't tell me that I shouldn't exercise. In fact, most of my fellow polio clinic friends are active people who do limited, structured exercise prescribed by clinic doctors on a schedule which they, themselves, monitor under the supervision of the specialists.

One medical researcher, Dr. James Agre, who recommends this approach explains, "The challenge in prescribing exercise...comes in recognizing these unique factors in each patient and modifying the prescription accordingly. One must protect very significant chronic weakness (in general, in areas where the muscles have less than antigravity strength on manual muscle testing) while exercising those body areas experiencing the deleterious effects of disuse. Weight gain is to be avoided if at all possible in this population, because increased weight only leads to further difficulty in the performance of daily activities." (18, p.331)

We need to take note that, according to Dr. Agre, disuse can be as harmful as overuse. One of the polio women wisely called attention to this fact in phrasing her question, *"I need to know about exercise that would maintain the use of what is still usable."* Another asks, *"Generally I want to know about exercise. What does moderate mean?"*

She needs to hear Dr. Agre's advice to polio doctors. "Interspersing intervals of activity with short intervals of rest to avoid excessive fatigue appears to be very beneficial for patients...Excessive fatigue is to be avoided in such individuals because these individuals may have more difficulty in recovering from exhausting activity than do nonimpaired individuals." He finds that intermittent exercise and rest appear "to significantly reduce the patient's complaints of fatigue, weakness, muscle and joint pain, but may also possibly reduce the rate of strength decline." (Ibid.)

Remember the clinic study conducted by Dr. Maynard, described in Chapter 3 where polio people lost weight with a two year program of nutrition education and water exercise? He, too, discusses the warnings to be considered with exercise. "Although most

clinicians caution polio survivors about excessive exercise, modest improvement in strength has been shown to occur with carefully controlled strengthening programs. Benefits of flexibility exercises are almost universally acknowledged." (11, p.70) The exercise component included in his program was "designed to aid in strengthening and conditioning the participants' muscles and joints, to relieve stress, and to develop aquatic skills that could be used for lifelong conditioning after program completion. Each subject was assisted by two water-safety aids. Lifesaving jackets were worn and specialized equipment was used (e.g. hand paddles, dumbbell flotation devices). Some of the exercises used were arm circling, flutter kicking, walking pool length in water and back flotation." (11,p.72)

"I realize I can't do walking and leg exercises. I'm afraid of the water and don't swim but there must be something I can do?"

There is and she can find it where ever her interests lie. The range of activities engaged in by polio women is endless: one plants and cares for a garden; one uses a stationery bicycle; the artists among them sculpt or paint, play the piano or sing; some do their own housework; others volunteer time to church and community programs or hospitals. Although water affords us support and assistance in moving our bodies it is not the only way to be active and maintain our muscle strength.

"I do assigned and some yoga stretching exercises every other day. If I hurt from them I will stay off for a day or two and try again with greater care, adjusting the exercises to what my body can handle."

This approach to exercise, shared by one of the women who answered the questionnaire, exemplifies the essence of what Drs. Agre and Halsted are trying to tell us: 1) some form of exercise is important and manageable by most of us; 2) it needs to be "assigned" by a specialist who knows our physical capabilities; 3) we must learn from those specialists how to monitor our body's response; 4) and we need to pace ourselves, making adjustments when we overdo. Beyond that we all can be engaged in activities which we love and which keep us moving.

The other equally important part of our responsibility in staying active is understanding and practicing energy conservation. The value of this concept is explained by another Canadian polio survivor, Mavis J. Matheson, M.D. "Using our energy well can allow us to do more and do it better." (19,p.256). Her four principles of energy conservation include:

- prioritizing, doing what we want to do and delegating to others what we don't;
- planning activity for times when we have the most energy;
- pacing ourselves and simplifying tasks, going easy on our bodies;
- taking rests and stopping before we feel exhausted. (19,p.257)

She suggests that practicing these four principles can be made easier if we give ourselves credit for what we **do** accomplish, and if we learn to say **no** without creating

defensiveness in others. Finally she points out that setting limits to avoid pain and fatigue "is a statement of action" not failure; in doing so we accept responsibility for our well being. (19,p.258) To me that means both storing energy to use when I need it for an important activity and then making conscious decisions about when and how I will draw on that supply. You will note from my activity history that this is an new concept and skill for me.

Dr. Matheson's formula for energy conservation focuses on attitudes and strategies we can adopt to help ourselves. Another equally important energy conservation technique which we practice every night of our lives is sleep. One CFS doctor calls sleep "the restorer of our energy pool." (7,p.150) She reminds us that sleep has a major function in our survival. "It helps the body to regulate and synchronize itself", warning that "anything disturbing that cycle can be a problem," for instance body pain. (7,p.152)

Quentin R. Regestein, M.D. tells us that sound sleep is most beneficial. He points out that loss of deep sleep, characterized by logginess and the rapid eye movement observed by sleep researchers, affects impulse control "and we may gain weight because of an inability to control food intake." (20,p.38) This information is verified by the experience of one of the polio women. *"I eat for fatigue and comfort; my impulse control is not good when I am tired."*

Most of the 26 polio women reported adequate hours of sleep, 14 sleeping 7 or 8 hours nightly, and 9 reporting more than 8 hours of sleep. Six, however, noted that their sleep was not restful, often interrupted. *"I frequently wake in the middle of the night and can't get back to sleep. I think because I have to expend effort to move my body."*

"Body position is an issue because I have to fully wake up to turn myself. I wake up many times at night. Every time I move I have pain that wakes me up; muscle spasms keep me from falling back to sleep." Interrupted sleepers are going to feel tired during the day as well as frustrated at night. Some of them have discovered that their polio doctors are prepared to help them remedy these problems with body positioning techniques and medication. Hopefully these polio women can take naps to make up for lost night sleep.

The fatigue that represents tiredness, from lack of sleep, is a result of an energy imbalance; too much expended, "not enough conserved." (Note that for us with weight problems the issue is rarely "too little consumed.") In fact those with problems sleeping need to be careful not to try to address the energy imbalance with food, particularly the wrong kinds. According to the CFS doctors poor nutrition can exacerbate fatigue; particularly alcohol, sugar and, in some cases, dairy products. (8,p.160) One CFS doctor lists good nutrition as a priority in fighting fatigue, followed by physical fitness, restful sleep, a sense of pleasure and a sense of mastery.

Many of the women who responded to my questions about resting practices and naps were quite concerned about the polio doctors' recommendations to rest frequently, fearing a disruption in a sleep cycle which is working well for them. There were several

different interpretations by them of what the doctors' "rest" prescription means. Most understood it to mean "take naps" and some felt quite guilty about not following that advice, making excuses about why they couldn't or shouldn't. *"I would never get things done."* Some, like this one, find themselves "resting" when they don't expect to. *"I take naps in church, sometimes during the day, often by the TV at night."* Other variations on the meaning of rest were: *"sleep"*, *"get off your feet - do something less active"*; *"lie down when you need to"*; *"lie down at specified times during the day"*; *"sit"*; *"probably a 10 minute break after an activity."* From both groups of respondents 14 don't nap, 7 do and 5 occasionally lie down.

Napping, or short-term, total body relaxation, may be particularly important to those respondents who regularly experience the fatigue associated with the late effects of polio. *"I get tired very, very easily. Eating is the one thing that requires very little physical activity."* Dr. Halsted reports that this condition of post polio fatigue is usually described as "overwhelming exhaustion or flu-like aching accompanied by a marked change in the level of energy, endurance and sometimes mental alertness. (16,p.171) Another researcher points out that polio fatigue is not tiredness but increasing physical weakness, and loss of strength during exercise. (Ibid.) Dr. Halsted warns that many of his "patients sustain a level of activity more strenuous than their strength and endurance allows." He recommends monitoring activity levels and sleep through a diary. Polio doctors can help us make sense of such records, working with us to make adjustments where needed.

For those of us experiencing post polio fatigue the most important response is rest and relaxation because we are dealing with muscle weakness rather than tiredness. Muscle weakness fatigue is an enormous complication for those of us who are struggling to remain active. Body awareness is critical to this part of our weight management program. We must be active within the limits of what our bodies can handle, never pushing, consistently and constantly incorporating rest into our patterns of movement.

Being aware of my body in motion is a new skill for me. For years I have done everything in my power to ignore the motion of my body, the limp, the sway. My greatest horror was entering a room or store with a wall of mirrors, suddenly seeing myself in motion. The advent of video filming has helped me watch myself walk and become more comfortable with my rock and roll. Today I experience it more as my own unique dance step with a rhythm reminiscent of the movement of ocean waves. When I let go of the old emotional barriers, vanity and embarrassment, it's not quite so hard for me to maintain my consciousness of how I am using my body. Unlike physically normal people, whose actions are mostly involuntary, I have to will many actions in order to perform them. This is good; my polio helps me to be aware of what I am doing if I will let it.

Allowing myself awareness of body movement I can think more readily about my body mechanics; how I am sitting, standing, lifting or holding objects, walking and breathing. One of the best handouts I ever picked up at a conference was a 13 page document produced by the Community Physical Therapy organization in Canton, Ohio.

entitled, Positioning for Comfort During Work, Leisure Activity and Rest.⁽²¹⁾ The principles recommended are good answers to most polio women's questions about movement and rest. They are recommended to prevent pain, maintain ease of movement, and reduce energy requirements. " The first and most important principle is to move into a new position (sitting, standing or lying down) every 15 to 20 minutes to avoid strain, fatigue and joint stiffness." Note that they recommend **moving!** Your mother taught you the second principle, "use good posture." The third tells us to "use the largest and strongest muscles possible in performing any work."

These principles are followed by very specific guidelines on how to position our bodies when sitting, standing, lying down or working. Good body mechanics also can be learned by working with physical and occupational therapists, preferably ones who know something about polio. I, personally, have had negative experiences in sports medicine therapy centers. Pacing, rest, sleep and body mechanics are all important aspects of weight control because they help us maintain an activity level commensurate with our managed food consumption. Energy conservation is **not** immobility, not a reason to stay home and sit all day, but an educated pattern of exercise and rest, movement and relaxation.

The final, often hardest for us but equally helpful and sometimes best, method of energy conservation falls in the category of accepting support. Polio people define support as braces, crutches, canes and corrective shoes. Remember there are also scooters, electric wheelchairs, bed boards, pillows, towel rolls, stairglides, rolling carts, reachers, shower chairs, recliner chairs, cruise-control and hand controls, and remote controls. Technology has provided more aids to movement and body support than the pocket book can keep up with. Although our timing was wrong for Salk and Sabin, it is right for these support systems which can do a lot of work for us, or allow us to do work in different, more energy efficient and muscle protecting ways.

In our lifelong battles to remain independent, we occasionally lose a war or two which we don't have to lose. Complicated as they may be in their responses to our physical differences, other human beings may be the best resource we have for conserving energy and staying active. I have gone through three stages in developing my skill in harnessing people power. First I had to learn to ask for what I need. Then I had to learn how to ask in a way that would provide a close approximation to the results I wanted. Third, I had to learn the principle of "passing it on." Once I realized that reciprocity or payback is unrealistic as well as usually impossible, I no longer had to feel guilty about accepting services and kindness from others. I know that I, too, can be of service, probably to someone else in some other way. I have learned to wait until someone opens the door for me. I can always give them a warm smile and "thank you."

People in stores, neighbors, family, friends, counselors, clergy, dietitians - every functioning human being can play a helpful support role in our polio lives, if we let them in and **show them how**. In accepting help I have learned how to be alert, cautious and selective by listening to hear what those people offering help say to me. If I hear words that feel like implied judgment or oversolicitousness I back off as fast as my scooter will

reverse me. There are people who have big problems of their own which they need to be working on, problems which can get in the way of their being able to help me. Practicing this caveat, I have grown in my ability to accept help and can delegate when appropriate. I have learned that the best way is to be proactive, selecting who I want to help and telling them how.

Support for my polio needs come primarily from the knowledgeable and experienced medical team in the polio clinic. I am fortunate to live 20 minutes away from a polio facility, but geographical distance need not be a problem in getting excellent polio care. Recently I met a clinic patient who is only a vacation away from his preferred polio team. In October, when it's time for his annual check up, he and his wife stock their mobile home and leave Illinois for their 'Fall leaf' vacation on the East Coast, spending one day at the clinic while passing through town. A fine example of using another polio competency, creativity, in meeting his needs. For our weight management issues that have to do with movement and activity, probably only a polio clinic has comprehensive solutions.

If we allow ourselves to constantly relive the initial polio experience, putting ourselves in isolation from other people, and specifically polio people, we are robbing ourselves of the magical support of a community of experts. Common experience, empathy and shared solutions to similar problems are helpful, restorative and affirming. Within a support group of peers who move like us, act like us, feel like us, who accept us and our experience, we can peel away the layers of heavy armor which we have been carrying around, along with our body weight, and truly begin to restore our balance. I first learned about support groups by joining those which had to do with overeating and relationship issues. When I realized that the real issue in my life was polio, I found a polio partner; together we created a polio support group which meets our own needs and those of others.

Two polio researchers in Australia, Drs. Mary Westbrook and Diane McIlwain have recently reported findings which confirm how unlikely we are to ask for human support. In a survey of 176 polio survivors they asked respondents how helpful they found specific strategies used by polio people for coping with the late effects of the illness. The larger numbers reported resting more, reducing activity and pacing activity as their preferred, helpful strategies, as were becoming informed, sustaining interests and finding new ones, developing a life philosophy and becoming more spiritual. The category of strategies reported to be least chosen and less successful were in the interpersonal realm; talking with friends or family, and asking for their help. (22,p.65-66)

Using the human support component of energy conservation is for many of us a painfully humbling experience. We have struggled so long with the shame of being different, of not being whole and of deeply felt powerlessness. Our pride is fragile, being grounded in fears about our unacceptability and wobbly assumptions about the effectiveness of compensation. Our misguided attempts to put so much of our limited but valuable energy into the appearance of being strong and independent, and extraordinarily

capable not only avoids the real issues of paralysis but doesn't work, in fact now works against us. Only by asking for therapeutic coaching, was I able to discover that humility, when distinguished from shame, can by connecting with others become a strength. The last chapter will explore emotional and spiritual help as a method of changing our eating/moving polio lives.

Do last chapters always provide the happy ending, the solution to the mystery, all of the answers? If you have read this far anticipating a final, simple answer to weight management problems, you may be disappointed. Answers are found, not in what I say, but in who you and I are willing to become. Just like you, I am in the midst of the sometimes chaotic, more often confusing, murky and fragmented process of becoming. Good days feel like progress; bad days, particularly when I temporarily lose my focus on healthy eating, feel terrible. On those days I understand and empathize with this polio woman's plea for help:

"I just can't seem to 'shake' off any extra pounds. I feel like a 'bubble' in the middle. Twenty extra pounds makes a big difference. I find myself feeling guilty about every bite and I don't like how I look."

If only she had the power to "shake" it off, I know she would do so in a minute. In this daily dilemma of trying to control weight, with apparent powerlessness over food, we fall so easily into the trap of guilt and self blame. Instead I have found that some of my strength to cope and change comes through understanding that eating is not a moral issue. I am not a good or bad person based on what I eat; what I eat only determines whether I gain, lose or maintain pounds or ounces. I am only doing something "bad" in a moral sense if I knowingly and willfully hurt myself or others through my abuse of food and am **not** willing to change. When we demoralize ourselves with undeserved blame and punishment, we get stuck in our powerlessness and can't change. We need to acknowledge that what we want for ourselves is very difficult to accomplish; it is a life long challenge.

One reason for the difficulty we face was not mentioned by the questionnaire respondents and should not be ignored. Overeating the wrong foods has been part of our American culture for over half of my lifetime. Everyone around us is doing it. "On any given day, at least one out of every four Americans is on a weight reduction diet...The average American has gained about 2.25 kg (5 lb) over the past decade or so." (4,p.276) The nutrition doctors at Mt. Sinai Hospital tell us that half of the adult population is overweight. (2,p.271) According to former Surgeon General C. Everett Koop more than 50% of Americans need to lose weight. (ABCTV/GMA) No matter how accurate the estimates, clearly my sample of polio women reflect a serious problem in the population at large.

Our exercise researcher, Dr. Agre was interested in and cited a recent study of Swedish and American post polio patients where "it was found that the average American (but not Swedish) post polio patient gained four kg of body weight in a four year interval. The Swedish subjects did not gain weight during this interval." (18,p. 375) Dietitians say our problem is that technology has made Americans sedentary (4,p.276). However, I wonder if the Swedish post polio patients are any more active than the Americans? If not, the difference between the two cultural groups is more likely to be found in the quantity

and quality of our diets. We tend to eat like our American countrymen and women and like them we gain weight.

Beyond cultural influence we need to understand that we may gain weight because we are **polio** women with **polio** feelings. When attending a GINI International Polio Conference I had the great good fortune to be drawn to the work of and then to meet Mary Westbrook, Ph.D., a fellow polio who has dared to investigate the emotional life of the survivor. She, more than any, has brought clarity to my understanding of my polio experience through her studies of societal responses to people with disabilities. Equally illuminating are her investigations into the psychological/emotional responses of polio survivors to the illness and their subsequent coping behaviors. Her recent, longitudinal survey following up 168 survivors, reports that "The feeling most frequently found in survivor's memories was anxiety. Overall 84% of respondents expressed one or more types of anxiety in their narratives." (23,p.7) Those remembered and even our unconscious past anxieties can be evoked all over again by our new experiences with the late effects of polio.

To the extent that we are living with past polio anxiety and present day stress from the late effects and are not dealing with those feelings, we may be compounding our eating problems. Psychologists confirm what overweight women have always known. Animal studies conducted by Robbins and Frey found that "eating reduces anxiety." (3,p.174) I would add "at least temporarily" to that statement. "Herman and Paley believe that any kind of stress, including the stress from successful dieting, can eventually lead subjects who are usually restrained to lose restraint and commence eating. This they believe can make it difficult to maintain restrained eating behavior for a long period of time." (3, p.173)

We might conclude from these studies that a significant part of our problem comes from our polio body's inability to cope with the eating-living style of our culture, with anxiety and stress being major triggers for our abuse of food. I know that I have bought into some stress provoking cultural myths in my lifetime:

- that I need to be self sufficient; I don't need others;
- that winning is important, winners being determined by the Miss America Pageant and the World Series (and we never were even "in the running.")
- that the word pace only goes with the word fast, as in jet travel and overbooked living;
- that women, particularly as they get older, need to get better.

Today I take note that these cultural myths have to do with living on the edge, at the extremes. Today I feel closer to the truth and less close to the edge, a frightening place to be when you have poor balance, by reminding myself what my thinner polio sisters know, that moderation in eating, in activity, in living is an alternative which I can choose more frequently.

According to Dr. Westbrook's surveys, polio has left us with a legacy of feelings, like anxiety, which if ignored and untended can cause emotional stress which we may be feeding. The most difficult emotional task for me has been resolving my anger, first at the injustice of polio, then with my physical limitations, and finally with losses sustained. I spent too many years acting out my anger, instead of acting on it by letting it fuel my commitment to change myself and my life. My anger always overwhelmed me when I was unsuccessful at controlling others. The frightened six year old, whose world turned upside down one day emerged from "recovery" determined to never let such a thing happen again by becoming all powerful and by controlling everyone in my realm. Not by accident did I become an elementary school administrator.

Ironically through tending to my problems with weight control, in overeater support groups, I discovered the truth about control. Polio didn't make me any more powerless than anyone else. Ultimately we are all powerless. I cope better with my polio and my food when I let go of control, and subsequent anger, and ask for help from a "Higher Power." In the beginning this concept felt uncomfortable to me. Only through acting on the belief that I am a part of a larger plan which I do not control, have I grown to understand that even though spiritual truths are not subject to scientific method, there is still evidence for believing. More times than not when I am being pulled like a magnet towards the convenience store for ice cream, but I pause to pray, "God help me to know what I really want," I drive instead to my home feeling "full" of something other than sugar, something far more sustaining. I do find that some of the hunger I feel can be filled by seeking connection with a dependable, loving God through whom the meaning of my polio life is revealed.

When I talk about finding spiritual help for our food issues I am not necessarily recommending organized religion. Books, spiritual healers, spiritual friends, and organizations like Spiritual Frontiers International are resources to be investigated in fine tuning your personal life philosophy, one which supports and guides you through your most difficult times.

"Weight limits my mobility, aggravates my arthritis, adds to stress. I gain because of family stress; family socialization taught me that food soothes. Weight loss requires consistency which is difficult in a life of upheaval."

All of us live with stress and upheaval, but some live with more. As I said in the first chapter overweight polio women often have had to deal with a combination of life events which can trip the precarious balance of a polio person. Here is where we need spiritual help, and sometimes therapeutic help, to provide guidance and comfort, while we reach for our inner strength. A Weight Watchers counselor, who had lots of contact with polio survivors through a second job once said to me this seeming paradox. "Polios want to be in control of themselves, of others and they don't want to hear what they can't deal with, but they are the most spiritual people I know." I think that she saw in us that part of spirituality which I call survivor's faith, a perspective that values life whatever the circumstances, because we survived. Perhaps we can tap that source of strength, our

polio faith, when we are suffering most from the physical and emotional pain of being overweight with the late effects.

Women who are overweight and who can't stop eating are suffering. Polio women who wake up and go to sleep with aching bodies are suffering too. In a church bulletin I discovered a philosophy of suffering, spoken by a spiritual young woman who says, "There are two kinds of suffering...They both have a purpose but one has a more important purpose. The first kind of suffering is chronic; it's a defense against change. The other kind of suffering is closer to grief, and its purpose is to help us close some doors and open others. My goal is to turn the first kind of suffering into the second so that I can accept and even welcome change."

I recognize her first kind of suffering as the part of me who doesn't want to change anything for fear of hurting even more. When my suffering is chronic, I think I am protecting myself, but I'm not. Her second kind enlightened me because I thrived for twelve years of my early life in a school whose Biblical motto had served my childhood needs so well. "Behold I have set before thee an open door." At this end of my life it is equally liberating to be given permission to close doors so that others can be opened. Resolving my food problems in some way depends on my ability to close some doors and open some new ones which will help me cope with post polio issues.

Three doors that I am closing are "keeping up", being "the best", and self sufficiency. Keeping up was the metaphor for my life for too many years. Always limping along behind friends and family who refused to adjust their pace to mine, I ached from the physical effort of keeping up and the ultimate truth that I couldn't. I envied couples who could walk along, hand in hand, matching stride, while my hands were occupied with my balance, crutches or canes. Because of doors which I am riding through today, I can bring closure to some of those old methods of coping. The doors newly opened are giving me access to human connection, asking for help, and humility. For me humility is the ability to live with my polio shame so that I no longer have to be the best.

I want to explain my humility door more fully to see if it has a polio context for you. I never could understand emotionally why the "meek shall inherit the earth." From my polio perspective humility would be an outward expression of my secret shame, to be avoided at all costs. My shame was based on being damaged and never fully healing, a condition which I knew was unacceptable to the undamaged human beings sharing my world. My polio stance of "denial" was an extraordinarily fruitless effort to hide not only this physical condition but my shame as well. In an essay, Chronic Illness and Shame, co-authored by an MS survivor, Kitty Stein, she shares her increasing struggle with shame as her disability progresses in a world which values "taking care of oneself", maintaining vigorous health even as octogenarians, and not becoming "a burden" to our families and communities.

Our shame is subtle, usually reflected in little events when we see ourselves as weak, inadequate or wrong because of others' attitudes towards illness, disability and

obesity. It is falling down in public, or not being understood when I am a "poor sport", or what I feel when no one will take the empty seat next to me. When as a teenager I broke my leg, the bitter-sweet roses sent to me by my aunt were accompanied by a card that read, "Shame on you!" For those of us with more flesh than clothing can hide, we have swallowed a double dose of shame. Shame is the product of the secret nature of our response to affliction, the hiding which does not afford us the comfort of healing relationships.

Kitty Stein's personal strategy for coping with shame has been to acquire what she calls her "nurturant voice." For all of us who have turned to excess food for nurture, Kitty Stein has a more promising kind of sustenance. She recommends "entering into a mutual, loving relationship with yourself. It means being empathic with yourself when things are hard. It means tolerating your shame, soothing yourself when you're disappointed, off balance or disoriented, uncertain, and so on. It means giving yourself enough time to adapt, protecting your use of energy so that you can do the things that are important to you. It means providing limits for yourself in an understanding tone. It means appreciating that you are more than your illness. It means being able to reach out for and receive collaborative support when you need it. It means appreciating all that you do for yourself that you wouldn't have to do if you weren't chronically ill or disabled. It means advocating for yourself both internally and externally when needed. And it means understanding how difficult it is to do all this and be supportive with yourself when you make mistakes and get upset." (24,p.117)

Is it not amazing that everything she says about living with the shame of her multiple sclerosis, can be applied to our struggle with shame because of the late effects of polio and our food behavior? Like Kitty Stein I have discovered that an important step in coping with the shame is to rob it of its power in secrecy. By speaking out and sharing our shaming experiences with polio, past and present, and with food we can find clarity, direction and support. By closing some doors and opening others I have found personal integrity, the wholeness that I lost when I was six. Today my life makes sense because I understand what food, my life source, my sustenance can do for me and what it can't. What it can't I take care of by learning other ways from other people:

- from my former therapist who first taught me about spirituality and shame;
- from people in support groups who showed me how to talk honestly about myself and my feelings;
- from my dearest friend who allowed me to grieve my polio losses;
- from her caring husband who referred me to a polio clinic;
- from polio friends who taught me polio humor;
- from polio doctors who tell me the truth with compassion;
- from polio researchers who have devoted their lives to finding answers; who are so willing to share what they know;

and from 26 women with polio who took the risk of talking with me about our shared food nightmare in all of its personal shapes and shades. I learned more from them than they will learn from me.

The spiritual message is that through others I am provided with what I need, when I am ready for the lesson. What I have learned so far is that even though my life is larger than my lifetime recovery from polio, that journey through recovery will continue to teach me what I need to know about my body, its feeding, its comfort and its care. I hope that this, my experience, helps you with your learning and your recovery.

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