

TRANSCRIPT FOR AGING WITH POST-POLIO  
subject to change without notice.

## Aging interventions

Anthropologist Ashley Montague once said "The idea is to die young as late as possible." *What you really need is a back-up body* Unfortunately, we don't have back-up bodies. In order to feel young, we must adapt to the changes in our lives. Today, I'd like to talk to you about making life changes in general and to suggest some options for change in the five areas that are the most effective with the least risk. These areas are, relaxation, nutrition, values and goals, communication and appropriate exercise.

### Making life changes

How often have you said to yourself -"I really should eat better, I need to learn to relax, or I would love to be able to communicate better" and how often have you not made any changes. If you are like most people, you lost count a long time ago. You may even have lost confidence in your ability to make changes. You can make lasting changes. To do so, you need to consider your options, set goals to get started and evaluate your progress.

Before you plan specific changes, figure out why you might want to change an old behavior or add a new behavior. If you want to build relationships, maybe looking better is not as important as improving your communication skills. What is the best way to get what you really want? Don't base major life changes on the latest self-improvement trend, magazine article, or TV ad. You wouldn't buy a used car from the first salesman you met. Why would you take health care advice from somebody trying to sell you something? Don't rely on individual testimonials. (If you only hear from the guy who wins the lottery, you may believe that a \$1 investment will always get you a million!)

Do your research. Keeping an open mind is a virtue -- but as the space engineer James Oberg once said -- "not so open that your brains fall out" *The sign says "Ye Olde wishing well"* Does a suggestion seem to be reasonable. If it seems too good to be true, chances are it is. Have studies been done? What actually works? Has it been tried with people like you? (If your nerves are burning out, a vigorous exercise program is not for you, no matter how much good it did those university age students.) Let someone else take the risk and find out what doesn't work. Check your "downside risk" before making a change. What are the costs in terms of side effects, money, time and energy? What is the least stressful way to make the improvement you have chosen? The greater the risk to you, the more evidence you need that an intervention is likely to work.

Set goals for change based on what you want out of your life. Your goals should be specific, measurable, realistic, and truthful. Make very specific changes one at a time. What? How? Where? and When? do you want to make this change. Set a definite time and place to get started To see if you goals are measurable, ask yourself "How will I know if I have succeeded?"

Be realistic, bring modifications into your life gradually. Your body is a wonderful, complex, living system with many checks and balances. Radical changes beget unexpected adaptations. (If you decrease your caloric intake too rapidly, your body will decide you are starving. Your metabolism will slow down. You will burn fewer calories. Not only will this diet

not work, but future diets will be less effective!) Keep changes small. Turn one large change into a bunch of small changes.

Be Truthful with yourself about your commitment to this change. Rats live much longer (2 or 3 times normal) on a very low calorie diet (the equivalent of 1000 -1300 calories a day in humans). On a very low calorie diet, I may or may not live any longer but without the pleasure of food, it will sure seem like it. Ask yourself "Do I want to live with this for the rest of my life?" All change is stressful. Don't waste valuable adaptation energy on something you don't intend to live with for a long time.

Once you have made a change evaluate it regularly. Feel good about what you are doing right. Things won't always go smoothly. *Monday 8:30 AM: My first attempt to switch Evan to decaf has been a failure.* Value your accomplishments and appreciate your willingness to try to make changes. If a week goes by and all you have noted are the missed opportunities for change, congratulate yourself on your deepening awareness. Listen to your mind and body. Has the change moved you closer to your goal? No matter how carefully we prepare we will all make mistakes. If something isn't working after 4 months, chances are it is not going to work for you. (Because I didn't evaluate early, I stayed on a vegetarian diet for 2 years as I became weaker and weaker.) Learn from the experience, rethink your options and try something else.

When you decide to make your life better, plan your change based on your options. Set a time to make one small, permanent change. Evaluate the change regularly and appreciate the things you are doing right. If it is not working after 4 months rethink your options. "Life is like sex. If it doesn't feel good, you're probably doing it wrong" You can improve your life. Make that change now.

I reviewed many books and articles on aging and Post-polio Syndrome using the criteria I have just discussed. I would love to say that I discovered the magic pill that halts (or better yet reverses) the effects of aging. Unfortunately it just doesn't exist. I was surprised by how many of the medications tried in PPS have been or are being recommended as anti-aging drugs.

Some of the "anti-aging" pills tried and found no better than placebo in Post-Polio Syndrome are Prednisone, Human growth hormone, IGF-1 Insulin-like growth factor (the active agent in Human Growth Hormone) and Pyridostigmine. Bromocriptine has been somewhat effective in treating fatigue but is only recommended after lifestyle interventions have failed. Large scale testing of Bromocriptine has not yet done in Post-Polio Syndrome.

What I did find was that the safest and most effective anti-aging interventions will also help with PPS symptoms. They are relaxation, good nutrition, working from your own basic values toward your own goals, improving communication skills and appropriate exercise.

As we go through this handout, mark things you are doing right with a star, options you would consider changing with a check mark. Later, rank the changes you would like to make and start working on the one that is easiest or most important to you.

## 1. Effective relaxation

I have considered marketing a pill to treat PPS. You would take it after lunch. Then you would have to lie down for 1 hour and relax completely. I am sure it would be a very effective treatment. It wouldn't be better than placebo though.

Polio researcher, Dr. Paul Peach pointed out that "Weakness and fatigue are the body's way of telling polio survivors to rest." Drs. Bruno and Frick of the Kessler Institute found that polio survivors who comply with treatment--pace activities, conserve energy, take two 15-minute rest breaks a day, and use assistive devices (a brace, cane, crutches, wheelchair or scooter)-have up to 22 percent less pain, weakness and fatigue 18 months after therapy ends.

To treat your fatigue, you need to take time to rest. Nap (if possible) during the day, work fewer hours, and take longer vacations. Rest is the best known treatment for Joint and muscle pain. Relaxation is the classic treatment for stress. Using biofeedback techniques, you may learn to control the temperature of you extremities with focused meditation. Learning better breathing techniques may even help with respiratory insufficiency

The risks of relaxation are very small. There are no known side effects. It is free or at most the cost of a relaxation tape. It requires a relatively small amount of your time each day. If done correctly, it should give you more energy. This really does sound like the magic pill!

Specifically you need to learn a range of conscious relaxation techniques. There are many ways to achieve deep relaxation but the common ground is slow, full, relaxed breathing, conscious relaxing of the muscles and focusing of the mind on one specific thing so that thoughts and emotions become quieter and less distracting.

Ideally you should learn at least one 20 minute relaxation technique, one 5 minute relaxation technique and one 1 minute relaxation technique. Once you master these relaxation techniques you can learn to recognize difficult, high stress situations and use relaxation techniques to help you to perform better. Use relaxation over the long haul to lower your day-to day stress level and increase your awareness of your body and your emotions. Your physical and emotional pain is information essential to your health and well-being. Pain is a language, learn to understand it.

Another way to increase relaxation is to incorporate relaxing behaviors into your life. Behaviors like laughter can be very relaxing. It was a seventeenth-century British physician who said "The arrival of a good clown into a village does more for its health than 20 asses laden with drugs." Norman Cousins discovered that ten minutes of the Marx Brothers could reduce tension for as long as 45 minutes.

Dr. William Fry, a Stanford University researcher, conducted studies during the seventies and eighties. He showed that both heart-beat and blood-pressure increase during "mirthful behavior"; (that is, chuckling as well as laughter). After this "excitement phase," a "relaxation phase" sets in. In the case of blood pressure, for example, immediately following laughter both systolic and diastolic pressures return to "lower" levels than the original resting levels before the onset of laughter. He found there is a correlation between degree of relaxation and the intensity and duration of the laughter (with or without actual delight or entertainment), which demonstrates that the action rather than the mood is responsible for the shift. Forced laughter has the same benefit as real laughter. I need not emphasize the importance of laughing loudly at cartoons whether you

think they are funny or not. *I believe in the healing power of laughter, Doc, but if you try to tickle me again I'm going to belt you.*

Sleep is an excellent form of relaxation. If you find you fall asleep when you try to do relaxation exercises, it is probably your body telling you just how tired you really are. Music soothes the savage breast. "The Mozart Connection" by Campbell looks at the use of music for relaxation. *The good news is you have a song in your heart.* Massage (will be discussed in the healing touch workshop). It is one of the cornerstones of some Post-polio programs. Be careful not to wear yourself out getting to the massage session. Hot tub, hot bath, and whirl pool baths are another very good way to relax. I like the relaxation of a dinner out. I also find listening to tapes very relaxing. I prefer murder mysteries. Loving is an excellent way to relax. It can be anything from petting your cat to hugging to sex. As Richard Bruno suggests, "Turn off your thoughts, turn on your body and JUST DO IT!". Do whatever works for you. *I'm not pointing any fingers, but all our bubble wrap has been stolen again.* The important thing is not the behavior itself, but that you find it relaxing and give yourself permission to do it more often.

The reason I have put relaxation first and spent the most time on it is. "When you are up to your ass in alligators it is hard to focus on draining the swamp." In stressful situations like the changes of PPS, blood flows away from the areas of the brain responsible for problem solving and information processing, impairing these faculties. Because of increased adrenaline flow, you will start to have trouble concentrating and difficulty staying still. This doesn't leave you in very good shape to learn new skills or identify your values but you can still learn relaxation techniques.

## 2. Nutrition and Vitamin-mineral supplement

Last October, Dr. Susan Creange, a research fellow at the Post-Polio Institute at Englewood (New Jersey) presented a study of diet in polio survivors. Dr. Creange found that, "Polio survivors often have a 'Type A diet,' drinking three cups of coffee for breakfast, not having lunch and eating cold pizza for dinner." When they put polio survivors on a hypoglycemia diet, that requires eating protein at breakfast and small, non-carbohydrate snacks throughout the day, they had a remarkable reduction in nearly all the symptoms of post-polio fatigue."

Your body's energy comes from the food you eat, so you want to make sure your food intake is nutritious. Too much weight aggravates stress on joints and muscles and increases pain. *I see you're developing a hazardous waist.* Difficulty swallowing may influence the way your food is prepared but makes it even more important that the food you eat is nutrition dense.

I experienced rapid progression of weakness on a vegetarian diet. When I began to eat red meat again, I experienced increased strength, increased muscle endurance and less pain. I also had less fatigue. Dr. L. Halstead described a similar experience when he presented his revised diet principles at the GINI 97 conference. He found that when he increased his protein intake, including more lean meat, nuts, fish, etc. in his diet. He was able to increase calories. He decreased fruit for fruit's sake and nutritionally empty snacks. These changes resulted in improved muscle endurance, diminished muscle pain, and his weight remained steady.

In his book on aging - Dave Barry asks, "Are you willing to commit yourself totally to a program of regular exercise, close medical supervision, and the elimination of all nicotine, caffeine, alcohol, and rich foods, to be replaced by a strict diet of nutrition rich, kelp-like plant growths so unappetizing that they will make you actually lust for tofu?" Many people see nutrition in these terms but it doesn't have to be that Draconian.

The basic principles are:

Eat a variety

of unprocessed (and little processed) foods

with high nutrient density

in moderate amounts

during at **least** three regular meals a day, including breakfast,

with protein at each meal

combined with smart snacking patterns (including beverages)

while drinking at least six glasses of fluid daily, two of them water,

and taking a broad-based vitamin-mineral supplement.

I don't recommend megadoses of anything!

*You have to much Vitamin C in your system. I'm prescribing a cold.*

Because you may be physically inactive, you may be at increased risk for osteoporosis. *That's not the kind of bone loss we talk about.* I recommend increasing you intake of dietary calcium. You may want to consider estrogen (Premarin and too many other names to mention). Estrogen replacement in women is probably the nearest thing we have to an effective anti-aging drug. It decreases bone loss, reduces the risk of heart disease, decreases the risk of Alzheimer's disease, reduces the risk of bowel and ovarian cancers, improves the suppleness of the skin and can even improve your sex life. There may or may not be an association between estrogen replacement and an increased risk of breast cancer. When I reach menopause, I plan to start taking estrogen. If

you can't tolerate estrogen then ask your doctor about bisphosphonates like Alendronate (Fosamax). These are fairly new drugs that can be used to reduce bone loss.

There are a few other things I would like to suggest under nutrition. I recommend you decrease your caffeine intake so you can monitor your fatigue more accurately. I also suggest you use alcohol in moderation. Alcohol inhibits swallowing, interferes with nutrition, and causes falls and accidents. Alcohol at bedtime interferes with the quality of your sleep. If you smoke, QUIT. *He doesn't like it much, but it is the only place I let him smoke.* If you are a smoker, quitting smoking is the most effective anti-aging intervention you can make. If you don't smoke, great.



### 3. Values & Goals Clarification

Gen. Douglas MacArthur said "Nobody grows old by merely living a number of years. People grow old only by deserting their ideals." If you are aware of your major long term values, you can adjust your specific goals to your new limitations without feeling you are losing what is essentially you. Once you clarify your own values, you can set goals within your strength or endurance limits, and avoid going repeatedly to that limit. By doing so, you can reduce the fatigue, joint and muscle pain, muscle weakness, and psychological stresses of Post-polio Syndrome. You and experienced physical or occupational therapists can determine functional losses, assess extremity function, evaluate daily activities, and the need for assistive devices to help achieve the highest level of functioning possible. Even minor adjustments like changes in hobbies or modes of transportation can help. If you are aware of your basic values as you consider possible adaptations to your lifestyle you will find making appropriate adaptations much easier.

*Can you at least tell me what our company strategy is? No, I don't want you to lose hope.* This cartoon is funny because we see the futility of working without goals yet many of us do exactly that in our personal lives. When you decide to clarify your values, begin by identifying 5 core values. A core value is an aspect of life that is particularly important to you. It may be something like being confident, learning, being creative, time with family, time with friends, exploring the world, success, helping others, laughing and enjoying, being in attractive surroundings, being independent, getting recognition or being challenged. Be honest with yourself about what matters to you. Don't get trapped into living someone else's values.

A goal is a specific long or short term objective you set for yourself. Find concrete, realistic ways to express core values more frequently in your life. These are your "valued experiences," the things you really love to do. Prioritize your valued experiences and plan for specific action for opportunities to enjoy them. Make small, specific, concrete changes that reflect your core values. *The art of free hand drawing.* This gentleman has found a way to express his creativity in a very difficult situation. It was Katharine Graham who said "To love what you do and feel that it matters -- how could anything be more fun?"

## 4. Self affirming Communication

A satisfying long term relationship is one of the main determinants of a long and happy life. Good communication skills will help you to develop and maintain satisfying long term relationships. *I interrupt this program for a very brief message.* Self affirming communication means having the courage to reveal to others who you are and what you want, expressing yourself assertively and listening actively, and replacing self-defeating communication behaviors and styles with self-affirming communication skills.

The four major areas of communication are, nonverbal communication, self-assertive language, giving and receiving feedback, and active listening. *This makes my face hurt.* Nonverbal communication includes clear and appropriate voice skills. Your body skills may change with polio or Post-polio Syndrome.

Self-assertive language is used when you say I when you mean I. For example, I want you to... rather than It would be better if you... Use "yes" and "no" not long involved explanations. Don't explain or apologize without reason. Avoid the word "but" it negates whatever you have said before it.

Another very important communication skill is giving and receiving feedback. When you give feedback, avoid value judgments by describing a situation. Be specific with your concerns. Report the impact of a behavior without judging the behavior. The best feedback is solicited, focused on things that can be changed, and immediate. When you are getting feedback, get more than one person's feedback.

Active listening is much easier if you frame the conversation. Try to set limits and impose structure on the information you are receiving. Recognize that disturbance takes precedence if you are not comfortable standing, stop the conversation by explaining you need to sit down, sit down, and then continue the conversation. Try to listen to both verbal and non-verbal messages. Recreate what you are hearing and play it back to the speaker. *Oh they're very good talkers, but they don't listen worth a damn.*



## 5. Appropriate Exercise

Get enough exercise to prevent disuse atrophy, but not enough to produce overuse damage. Many survivors are prescribed or actually ask for the kind of physical therapy they had right after polio: exercising to the point of exhaustion. Several studies show that pumping iron will not increase the strength of muscles that are becoming weaker, and can actually cause an irreversible loss of strength.

After a 1997 study by A.J. McComas of McMaster University in which he actually counted neurons to assess damage, he warned, "Our findings make clear that polio survivors should not be treated using electrical stimulation that causes muscle contraction, nor should they engage in fatiguing exercise or activities that further stress metabolically damaged neurons that are already overworking."

In other words, No free weights, No exercise bikes, No tread mills, No NordicTracs and No Thighmasters for polio survivors. "Feeling the burn" means you are fatiguing your muscles. "Feeling the burn" means nerves are burning out. *Maybe you should ease up on your exercise program.*

With all this damage possible, one might ask why a polio survivor might want to exercise? Well, first, it worked for you after your polio infection. You may have been told regularly how much exercise made you strong. I know I was. You may have received a lot of encouragement and reward for exercising early in life. Lessons learned early in life, tend to be difficult to unlearn. You may hope to increase your life span. Life span is reported to average only 2 years longer in those who exercised as opposed to those who didn't.

Exercise is great if you can do it but remember if you can not exercise, there are other ways to get many of the benefits. Exercise relaxes your body and your mind and releases endorphins. You can get these results through meditation techniques and relaxation. You may want to exercise to ensure better health. To improve heart and lung function, you can use focused breathing. Good nutrition can very effectively control weight, reduce the risk of diabetes and prevent osteoporosis.

A good exercise program has a mix of suppleness, strength and stamina. Muscle stretching and joint range-of-motion exercises are important where there is muscle weakness. Stretching, helps decrease pain and increase range of motion. To improve your suppleness try gentle yoga or other stretching exercises

Do exercises for strength only with great care. Gentle, non-fatiguing exercises are useful for many polio survivors to maintain muscle strength and tone. If you are experiencing increasing muscle weakness, exercise only under the supervision of a knowledgeable physician or physiotherapist. Discontinue any exercise that causes pain, weakness, or muscle fatigue, including walking. To start an exercise program for strength, first, find out which muscles polio damaged. You build strength in the undamaged muscles using ordinary muscle strengthening methods. For the polio damaged muscles figure out how much weight will fatigue them. Then, lift only 30% of that amount with the damaged muscles. **DO NOT FATIGUE** the damaged muscles.

To decide if you should exercise for stamina find out if you can get your heart rate up to training range (220 minus your age) without fatiguing any polio damaged muscles? If you can, get your heart rate into training range for about 20 minutes about 3 times a week for stamina. If you

can not get your heart rate up to training range without fatiguing any polio damaged muscles, do not do exercises for stamina. You might want to try laughter. Dr. William Fry found that about 100 laughs a day is equivalent to ten minutes of rowing a boat for its aerobic impact. Sex can also be an excellent aerobic activity. If you only have the stamina for one aerobic activity let this be it! Always remember, with any exercise activity, adapt it to your level to avoid fatiguing you muscles.

There are **many** books on aging. The local library had three columns. Each of the local book stores had a whole section on lifestyle and aging. The books I found most useful are *Your Vitality Quotient*, Earle, R., Imrie, D., & Archibold, R., Random House of Canada Ltd., Toronto, 1989, *Live Longer - Live Better*, Reader's Digest Assoc. (Canada) Ltd., 1995, and *Reducing your Body Age*, Earle, R., Imrie, D., & Archibold, R. They have a web site: at [www.ivillage.com/bodyage](http://www.ivillage.com/bodyage)

We have come together (at this conference) to enjoy contact with and support from others with similar problems and to collect information. The information that we collect is most valuable if it can be used in our day to day lives. (As the conference continues, look for) information on these and other changes that might be valuable to you. Appreciate the things you are doing right Rank the suggestions in the order that seems right for you. Plan your change. Break it down into small, permanent changes that you can make gradually. This whole conference will be a success for you if you can make just one long term life change using the information you gather here.

"If you can't be a good example, then you'll just have to be a horrible warning"

Catherine Aird