

The Parkinson's

A Beginner's Guide to a  
Good Life in the Slow Lane

Challenge

by Jan Peter Stern

*To Irene*  
*whose love and friendship*  
*continue to give me the desire to keep*  
*my ship of life afloat*

Acknowledgments:

Included are many of the items my wife and I presented to the Westwood (Los Angeles) Support Group.

Thanks to my support group; to Chuck McElroy, M.D., Dr. Gayle Dakof, Devra Breslow and Dr. David McCann for their invaluable suggestions and encouragement; and to Darla Polfus for her invaluable assistance.

And special thanks to my family for their help in making this booklet a reality. They may also wish it to be known that the coping methods I describe are my goal, not necessarily my level of attainment.

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Edited and designed by Daniel M. Stern.

*This book is not intended to replace the services of a physician. Any application of the recommendations set forth in the following pages is at the reader's discretion and sole risk.*

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***A Good Life In the Slow Lane***

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## ***To the Health-Care Team***

**Dear Fellow Fighter:** This information will give you a hand in learning new coping skills, enabling you to cancel out much of this challenge with a “can do” spirit. You will be able to face the future with a renewed ability to embrace life.

**Dear Doctor:** Your diagnosis will loom large in the life of your patients, who may become depressed and isolated. Please give them this “beginner’s guide.” By providing access to resourceful actions you will re-ignite hope.

**Dear Family/Support Person:** By reading about the experience as seen “from the inside,” you may gain new insights towards becoming most effective in your caring and love. You are an essential member of the health-care team.

## *Introduction*

**T**hese pages on Parkinson's come out of my thirteen years of coping with it. For the first few months the diagnosis overshadowed my life with feelings of gloom and hopelessness. Only when I began to write down my ways of coming to grips with "the Challenge" (as I prefer to call it), did I gain a more objective view. I believe this point of view is what still saves me from breaking under the load of virtually *everything* becoming more difficult.

Writing this booklet, along with the loving support of my family and friends, has helped me reach a new, positive outlook. I've learned to truly believe that although I may not be able to control what happens to me, I *can* control what I do about it. Thus, I continue my search for the most effective ways to cope as I go forward in my marriage, my role as a father and my career as a sculptor.

# C H A P T E R O N E

## *The Learning Experience*

*“The best thing about the future is that  
it comes to us one day at a time.”*

— Abe Lincoln

### *Handling the Diagnosis*

At last, I learned it was not rapid aging or clumsiness that had quietly intruded into my life.

My symptoms had become far more obvious, but it was only after a traumatic event—being pushed “over the brink” by the terrifying experience of a large dog biting me in the face—that a correct diagnosis was made.

Actually, five years earlier my lack of balance caused painful falls while bicycling, roller-skating and windsurfing. Gradually I was walking with my left arm not swinging and dragging my left foot. These were all signs that would have spelled out Parkinson’s to a neurologist, but none of these events by themselves caused me to see one.

It was only after the dog bite that the total picture became clear to my astute wife, Irene. The muscle tension in my neck, chest and arms, which *seemed* to be caused by the attack, was not relieved by any



## *Handling The Diagnosis*

relaxation technique. Irene researched the puzzling condition in medical books and determined that it was most likely Parkinson's. We then received several confirming diagnoses from neurologists.

Parkinson's became a new reality that we had to learn to live with, and yet it took us many months to accept the diagnosis. All too vividly in our minds was the image of my uncle, a physician, who left life the hard way, after a twenty-five year fight (just as L-dopa medications were becoming available).

Fortunately, the memory of his predicament has been replaced with current reality: the prospect of a greatly improved quality of life, thanks to new medications and a focus on *remaining active*.

To me, the good news is that since Parkinson's usually progresses very gradually, we all have a fighting chance to learn coping strategies along the way. My own spirits and self-confidence have actually *steadily risen*, even while I must learn to handle each new aspect of the challenge. This is the path I would like to help every fighter to find.

I've learned that Parkinson's has even brought me some unexpected *benefits*. My elevated blood pressure has come down to normal, reducing the risk of strokes. Since I use much more energy in all movements my caloric intake must increase

## *Handling The Diagnosis*

and I can once again eat most of my favorite foods. All my previously loose joints have tightened up; I no longer dislocate shoulders and ankles with the slightest jolt.

It has also been my experience that at moments of danger a brief, swift reaction time may be available to my slowed-down body. This can occur through the immediate and automatic release of adrenaline to permit necessary actions.

A late diagnosis of Parkinson's had the advantage of sparing me the burden that knowledge of it brings. It is just as well that this was delayed until the time for medication (amantadine) was nearing. Also, with the delay, diagnosis was possible with greater certainty.<sup>1</sup>

### *Conveying the Diagnosis in a Supportive Manner*

For some years after diagnosis, whenever I heard or read the words "Parkinson's disease" it hit me hard. The "disease" part made it sound like a verdict. It is with good reason that in most support groups this second word is no longer used in the name of the organization.

Dr. Parkinson first described our problem in detail in his book of 1817. "Parkinson's disease" is a

<sup>1</sup> I talk about the benefits of late diagnosis in light of the fact that there is currently no way of curing or preventing Parkinson's. However, when there are predictive tests and ways to prevent or cure it in the future, an early diagnosis will certainly be desirable.



## *Conveying the Diagnosis in a Supportive Manner*

useful term for medical precision and fund raising, but it is demoralizing for those of us who are so categorized. I was troubled with this problem of being labeled with Parkinson's disease until I started to look for an alternative name for it. By focusing on muscle tension, which for most of us is the most conspicuous and self-treatable feature, a sense of doom can be avoided and active optimism put to work.

I want to encourage a search for a better way of naming our particular health problem. Instead of saying "disease" it is much more helpful to call it a "*Muscle Relaxation Challenge*."

### *To the Family/Support Person*

The sensation of Parkinson's is said to be like a yo-yo, an up and down experience in which it may not be possible to do what was easy a few minutes ago—and will be easy again a little later. Whenever it is not essential for something to be done immediately, the support person should resist the temptation to help. Hold back on saying "let me do it for you, I can do it faster." This restraint can give your partner a big vote of confidence.

Encouragement is most effective and also builds the bonds of love ("It's good to see how well you walk"). This is shown clearly in the example of one woman who has Parkinson's. She spends half the year with an overly helpful child, the other half with an unrelentingly creative, lovingly nagging child.

## *To the Family/Support Person*

Thus she spends half the year in a wheelchair and the other half fully active. And this has been going on for several years!

As a support person try to let go of the inevitable guilt feelings for falls and injuries which you did not, and really could not have prevented by “always being there to help.”

If your caring becomes a round-the-clock task you *must*, for the sake of the relationship (and your own health and sanity), arrange for someone to regularly take your place for a few hours. This way you can take time out to revive your strength and go on with good cheer.

When a serious health challenge is faced, the quality of life can be diminished by living in a tentative way. In the Parkinson's experience I find it especially important to be on guard against losing my initiative, for I can easily leave it to my spouse to handle decisions and actions. To prevent this from becoming too heavy a burden on her, she keeps provoking me into involvement. She has become an active fighter for my health.

## *Learning to Preserve the Essentials*

### *Breathing*

My ability to swallow effectively and keep food out of my lungs is becoming impaired.

## *Learning to Preserve the Essentials*

Therefore, to prevent aspiration pneumonia, I do not tilt my head back or lie on my back while swallowing. *Vigorous coughing* clears my airway as soon as saliva or food is felt in my windpipe. I have learned and taught those around me the Heimlich Maneuver, a method for clearing the airway of a choking person. It works like popping a cork out of a bottle, with quick compressions of the lungs by pressing upward on the diaphragm.<sup>2</sup> (As with Cardio-Pulmonary Resuscitation, *simulate* it. Perform it ONLY on a person actually in need of rescue).

### *Balance*

I have learned how to prevent falls and how to fall with least injury (see *Falling*, p. 12). If I can no longer adjust to my environment, it must be periodically readjusted to my needs—for example, installing grab bars and carpeting in the home bathroom.

### *Sight*

Because my balance depends greatly on visual cues, it is essential to wear eye protection at all times of risk. Since I now blink much less often, I use glasses to protect the surface of my eyes from getting dried out in windy conditions.

<sup>2</sup> Refer to diagrams and instructions in the front of most telephone directories.



## *Learning to Preserve the Essentials*

I strengthen bonds with loved ones and friends so I need not fear being forsaken as I become increasingly dependent on them.

### *Independence*

Focusing on essentials like feeding myself, turning over in bed, bathing <sup>3</sup> and getting dressed preserves my independence of action. I hold on to privileges like driving a car by fully concentrating on demanding tasks.

### *The Support Group as a Resource*

*The place to find and give hope, courage and friendship; how to start a group*

I was very reluctant to make that first, crucial visit to a Parkinson's support group. I was fearful of being depressed by what I might see, and thought I was not yet in so "bad a way" as to need it.

In my early attendance of our own and other support groups, I was greatly relieved to see how very well people were coping after ten, twenty and even thirty years. My sense of isolation was relieved through the comradeship, which I find renewed in each meeting. Our group convenes for three hours *twice* a month (for continuity) in a church community room. We find this preferable to a medical setting.

<sup>3</sup> Set the hot water heater so the temperature at the tap is never higher than 140 degrees F. This will prevent accidental scalding, a very common and often lethal problem.

## *The Support Group as a Resource*

At every third meeting we have a one hour session in which the spouses are separated, those with Parkinson's and those without clustering in separate groups of four or five. In privacy we all can more freely air our fears and frustrations, gaining support in what is sometimes a very lonely fight. We stay in touch by telephone, responding to calls for help from the newly diagnosed as well as assisting old-timers. At each meeting we discuss new scientific developments and share coping hints.

To start a new group yourself, if none exists in your area,<sup>4</sup> contact local neurologists, hospitals and pharmacists to help find a nucleus of members. Reading Sid Dorros' book (see Reference Library) gave me insights into the unique gains I could only make by being in a support group. Even those who usually avoid people are now active participants.

We encourage a "buddy system" in our group. As in scuba diving and rock climbing, we pair ourselves off for mutual support. The telephone lines become our lifelines, especially when the going gets rough. It can bring solace and courage to know that there is someone who truly can be counted on to listen and *understand*—at any hour of the day or night.

<sup>4</sup> See page 45 for help in finding the support group nearest to you.

## *It is OK to Yell for Help*

### *It is OK to Yell for Help*

*Expressing fear and anger on those downer days;  
using safety vents*

On those *mumble, fumble, stumble days* I reach for someone who cares. Physical contact can be more meaningful and nourishing than any spoken solace. Writing down my feelings, even if just in a letter to myself, helps heal the invisible wounds. I keep a diary or journal as a dialogue with myself, writing down or tape recording my thoughts as they come tumbling out, uncensored. In this way my private sorrows can be expressed, spent and cast away.

### *Falling*

*A major threat to health*

You might say falling is when your body goes ahead without the consent of your feet. And when your feet try to catch up with your toppling body, a dangerous acceleration is added to the fall. In my case, this caused me to run head first through a glass door. When I fall I'm usually tired or not sufficiently awake. *Nighttime* falls are the paramount hazard to those of advanced age.

No longer can I afford to run, unless a life is at stake. Letting myself fall back into a chair is always tempting, yet should I miss the mark I'd make a crash landing! Keeping my weight forward as I lower myself makes for a controlled descent.



## *Falling*

The following contribute to falls:

- \* Forgetting to take medicine on time;
- \* Not standing in a stable (legs apart) stance;
- \* Knees locked, rather than slightly bent;
- \* Not lifting feet over even the smallest obstacles;
- \* Not adapting fast enough to a change in ground angle (especially when reversing direction from uphill to downhill);
- \* The body going in a different direction from the feet, as in making a sharp turn.

Balance is achieved in three ways: visual feedback from the space in which we are; the inner ear's circular canals, which sense the direction of gravitational pull; and the feedback from our foot contact with the ground. All of these are gradually impaired by age, but the last one is particularly disturbed by Parkinson's interference with feedback from one's position. Recent studies also indicate that a decrease in the ability to know where body parts are in relation *to each other* (and to the environment) may contribute to problems of balance in Parkinson's.

I find it truly amazing how suddenly my forward momentum can change into a downward plunge, hitting the ground before I can bat an eye. The most successful preventive strategies I have learned are these:

## *Falling*

- 1) Walking without shoes, when possible, for maximum feedback from the ground (I haven't fallen yet while barefoot);
- 2) When light-headed or dizzy on arising, placing head between knees to increase blood supply;
- 3) Learning how to instinctively roll my body into a ball as I fall, to reduce impact and protect the head (I learned from martial arts instruction);
- 4) Shifting weight from the foot on which I am standing only after secure footing for the next step is assured. I avoid even small leaps, as balancing becomes more of a problem;
- 5) Using automatic night lights in all parts of the house;
- 6) Removing all loose rugs and not allowing objects to be placed even briefly in walk paths;
- 7) Focusing on stairs by counting steps and always holding handrails;

(Bifocal lenses can interfere with visual orientation, especially when descending)



## *Falling*

- 8) Recently a physical therapist has helped me very much with special exercises designed to improve my sense of balance.
- 9) Always keeping an answering machine on, set to pick up on the 4th ring. This prevents having to run for the telephone;
- 10) Making sure ALL glass is safety-glass (or plastic) in places where I might fall into it;

Learning to get up from the fall gives me confidence in not having to lie there helplessly. I practice this by first lying on the floor, then getting up on my hands and knees and crawling over to an object that I can use to climb upright. Lowering the fear of falls reduces rigidity, which results in a more relaxed fall. This is helpful in avoiding serious injury.

## *Tremors*

### *Coping with the image*

Unless you have experienced living in a body that at times will not stop shaking, it is hard to imagine the burden which tremors can impose on the challenged person. It can give yourself and others the impression that you are scared or totally out of control.

Tremors are the result of numerous tiny muscle fibers contracting all at the same time. Before coping with Parkinson's I did not tremble except when shivering; my nervous system still had a



## *Tremors*

marvelous way of making sure that involuntary contractions occurred in a totally random way. This prevented the gallop of simultaneous contractions called tremors. For me, understanding this simple, innocent cause of tremors has taken away my fear of them. Whenever I remember to use relaxation methods I can quiet my limbs and head adequately for most tasks.

There is even an advantage to having a visible sign of my health challenge. Most people have serious problems that are “silent” or totally hidden, like diabetes or ulcers. Tremors make it unnecessary for me to tell strangers or remind my family that my performance may not be what I wish because I am coping with a problem.

Some people may interpret my tremors as a sign of weakness, or even guilt, when I handle a stressful situation face-to-face. Whenever I need to take a firm stand, I prefer to do it in writing or by telephone. Sometimes I can be represented by someone in an adversarial confrontation (for example, having my accountant stand in for me at an audit). If I have to do it myself I explain in advance why I may shake.

One of the first and most disconcerting symptoms of Parkinson’s may be an internal, invisible quivering. Relaxation techniques, including deep breathing, can greatly reduce these internal tremors, as well as the obvious ones.<sup>5</sup>

<sup>5</sup> See the section on *Relaxation*, p. 38.

When tremors do show, I aim to carry them proudly as a “badge of courage,” showing that I am bearing up under a great challenge.

I am resisting the temptation to increase my medication for tremors alone, keeping that option for more profound needs, such as mobility and balance.

Some tasks, such as shaving, may be difficult to do well when shaking. I leave these for a time of day when I am least shaky. Some people have learned to “transfer” tremors from one limb to another in order to perform tasks such as eating.<sup>6</sup>

The errors caused by tremors when touching telephone or typewriter keys can be reduced by not pressing but *striking* each key, as on a piano.

My limited dexterity and tremors have made flossing and thorough brushing of teeth and gums much less effective. This, combined with a dry mouth, makes frequent use of an electric rotary tooth brush and Water-Pik™ a *necessity*.

### ***Why Do I Feel So Slow and Weak?***

Some days I feel like I couldn't punch my way out of a wet paper bag! Yet I am actually far stronger than I seem to be.

In spite of some muscle atrophy, the major reason for my apparent weakness is that I am struggling

<sup>6</sup> See the book *IVAN* (Reference Library, p. 47).

## *Why Do I Feel So Slow and Weak?*

against *myself*. When I pull open a door I am at the same time unwittingly pushing it closed almost as hard with the residual tension in the opposing muscle! This is reassuring, almost amusing and something I can work on improving through relaxation.

The hidden force of the opposing muscles becomes quite obvious when I pull some items apart, like a banana from the bunch. When it tears off, my hands hardly move at all, instead of freely flying apart into space the way they used to do. The tension of these opposing muscles greatly slows down my motions and can be the cause of pain.

It is very frustrating to grasp five or six times for a pencil on the floor, or repeatedly slam my car door until I get it closed. Actions that used to be routine have become a challenge simply because the “feed-back loop,” the touch-to-brain coordination, has become less effective. Familiar tasks have to be constantly relearned.

Also, I am uncertain about how far off the mark my movements will be, due to sluggish feedback of information. My motions come in small increments: I slowly bring a fork to my mouth, as if in fear of spearing myself. At times it feels as though my view of the “control panel” that works my muscles is shrouded in a fog.



## *Lesser Known Symptoms Of Parkinson's*

### *Lesser Known Symptoms Of Parkinson's*

Parkinson's has many lesser known yet troubling symptoms, most of which I personally know. For example, urinary urgency, frequency and retention are often associated with Parkinson's.<sup>7</sup> If one wants to find out whether these conditions are being caused by this syndrome medical advice should be sought. There is a special concern in the case of men, where prostate enlargement may *seem* to be the problem, easily leading to unnecessary surgery.

Some of my most unexpected Parkinson's symptoms include: irritability and a wearing thin of my patience; having to concentrate on performing muscle movements one at a time; difficulty in preventing walking backwards; having a rather narrow range of temperature comfort, with excessive heat becoming instantly intolerable (best overcome by running cold water over wrists); being easily moved to tears; increased danger of choking due to reduced gag reflex; injuries caused by poor coordination, such as biting my tongue, cheeks, or lips; continuing to smell bad odors, sometimes for hours beyond exposure to the source; difficulty in finding a comfortable position while at rest; reduced sensitivity to the passage of time; leaving tasks unfinished, and a strong tendency towards apathy.

<sup>7</sup> See the book *Staying Dry* (Reference Library, p. 46).

## *Lesser Known Symptoms Of Parkinson's*

Recently I was surprised to discover that I needed hernia surgery (done under *local* anesthesia). I later learned it was straining during constipation due to Parkinson's that caused one of the two weak areas that all men have in the groin to give way. I have since learned from a physician how to apply external pressure while straining to prevent a recurrence.

Expression of sexuality evolves as I adapt to changes in my condition. The best treatment of this subject that I have found is in Jon Robert Pierce's book *Living with Parkinson's Disease*, pp. 69-76 (see Reference Library, p. 47).

## C H A P T E R   T W O

### *Attitude Makes the Difference*

*“Hope is the thing with feathers  
That perches in the soul,  
And sings the tune without the words,  
And never stops at all...”*

—Emily Dickinson

#### *Being Among Others*

*Telling others about what is changing in me: handling questions and sidelong, puzzled glances.*

Fortunately there is no social stigma, shame or risk to others in my having Parkinson's. I have gradually felt freer to bring out into the open the innocent reason for difficulty in controlling my body. A light touch of humor often helps ease tensions for others and myself.

One line I've heard that I like is: “If they try to rush me I always say, ‘I've only got one other speed...and that's slower.’”

A nice inside joke might be to print up for the support group some T-shirts, or pin-on badges, that sport the challenge:

*“Parkinson's Is Not For Sissies”*



## *Being Among Others*

In looking back, I feel (as do many of the members of my local Parkinson's support group) that we have been secretive for too long, hiding ourselves from others, instead of reaching out when we needed help the most.

It is possible to avoid becoming a recluse by making a sport out of facing an unpredictable, curious, and usually well wishing public. Here are some of the questions I have learned to respond to easily:

*"Do you feel alright?"* — Yes, this is normal for me...thank you for asking.

*"Do you have a bad back?"* — Sometimes.

*"When will you get better?"*  
— Some days are better than others.

*"Is it contagious?"* — Definitely not.

*"Why are you so slow today?"*  
— My muscles are stiff.

*"Did you have a stroke since I last saw you?"*  
— No, actually I'm just learning to live with Parkinson's (then I explain it).

I have had to learn how to gracefully accept help from others, especially when offered by strangers (usually more generously than needed). Whenever I project an image of being precarious and fragile, it does raise concerns in others about my safety. First I need to be clear in my own mind whether

## *Being Among Others*

it is safe to proceed with whatever I am doing; if it is, others need to be reassured that I can handle myself (such as refusing a chair when I appear unsteady).

Using a cane has served one member of our support group well. Though he does not need one, it has become a signal that he may be in need of help and that he walks strangely for a legitimate reason. It also can be of help in self-defense or to prop open a spring loaded door while walking through.

Carrying a letter from my doctor that explains my condition is important in certain situations. It cautions police against assuming that drinking alcohol has caused me to walk unsteadily to my car, drive slowly, or have difficulty staying in one lane. With this note in hand, officers are less likely to put me through the “walk the straight line” test—which I probably could not pass anyway.

Having a license plate with the designation “Disabled Person” has also helped to keep the police from wrongly stopping me. It makes life much easier since I can park in disabled parking places that are always much closer to my destination.

Loss of my driving privilege would be a very great burden for me. This loss has been so traumatic for some people in our group that it either was the precipitating factor that led to diagnosis of Parkinson’s, or has made the symptoms drastically worse.

## *Being Among Others*

As we age, we all ask ourselves, “When do I voluntarily give up driving?” For most people this privilege is closely tied to their feeling of self worth. Talking it over with others in a support group may offer helpful perspectives. The bright side of not driving is the benefit of more walking. If one's license has not been revoked, a transition period of slower-speed driving on local, familiar streets can be a safe morale booster. The Veterans Administration and some occupational therapy centers offer valuable evaluation and retraining programs.

Traveling is an adventure that I will pursue as long as I possibly can. These days, especially in the United States, people and facilities are geared to cope with my special needs.

It is only in the past decade that people with all kinds of health challenges have ventured out of hiding. *Let 's all take our rightful place in the mainstream of life!*

### ***One-Task-A-Day Menu***

I used to be overwhelmed by *all* the ways in which life now has to be “performed” instead of flowing effortlessly as it used to. Now I use a simple plan that can greatly reduce frustration. I choose just one item per day which I need to improve. Here are some examples:



## *One-Task-A-Day Menu*

- \* Breathing deeply ten times every half hour;
- \* Walking with such long strides that I am forced to swing my arms;
- \* Walking erect, as if hanging by a lock of hair;
- \* Writing clearly, with penmanship and pride;
- \* Pretending to be a radio announcer for a day; speaking with an exaggerated enunciation that makes people perk up and listen; going all day with no one asking, "What did you say?"

To reinforce this regimen, I let others know what my selection from the "menu" is that day.

### *Goal Setting and Rewards*

If life is to continue to have meaning, rewards must be given high priority. Just because everything takes longer to do than it used to is no reason to forego those things that make life a joy.

Like rungs in the ladder of life, my goals and rewards are set for the next hour, for tomorrow, for next week, for next year.

I attempt and often succeed in tasks that now seem almost impossible, such as catching a moth, or tying a double knot in my robe in the dark. Victory is all the sweeter for the effort expended.

*I reward myself daily with pleasure and laughter.*

## *Communicating*

### *Communicating*

#### *Relearning effective talking and writing skills*

For me, relating to people is what being alive is all about. Yet, with Parkinson's, the opportunity for this interchange may be greatly diminished.

We depend on facial expression for clues to each others' thoughts. Since I tend to stare with a seemingly expressionless face (which can give a false message of sadness, indifference or anger), I *must* use words to let even my family know what my true feelings are. Recently I succumbed to the convenience of not shaving, except around my mouth and upper lip so as not to hide all expression.

To offset my tendency to speak too softly, I try to speak two or three levels louder than *seems right* to me. Training sessions with a speech therapist have been helpful. To practice clarity, I enunciate the alphabet and numbers. I stretch out vowels: *Aaaaa, Eeeee, Iiiii, Ooooo, Uuuuu*. I do this in front of a mirror, with maximum jaw movement. By listening to a recording of my voice, I can learn where improvement is needed.

To improve clarity of speech, tongue exercises can be done in private, odd moments of time. I move my tongue side-to-side, rotate it and exaggerate all normal movements. I may need to use my fingers to guide my tongue, and a mirror. Also, I make sounds like *pa-pa-pa, ta-ta-ta, ka-ka-ka, da-da-da,*

## Communicating

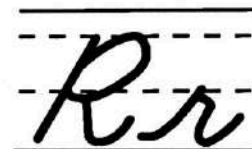
*ba-ba-ba* and *ga-ga-ga* to coordinate lips and voice production with the tongue. I then use rotating motions of neck and shoulder to relax the whole area.

Chewing gum, or preferably flax (linen) seeds, aids the agility of the tongue, lips, and other muscle groups needed for effective speaking and swallowing. I am planning to join a folk singing group, for an enjoyable way of improving my speech and breathing habits.

The telephone is my link to the world. To remain audible and hear well while writing down information and shaking, I use an operator's head set, supplied free by the telephone company to disabled people. Local telephone directory service is also free, with a doctor's verification of special needs. A voice amplified telephone makes me heard on long distance calls.

To speak louder I must increase my ability to expel air. A simple exercise is to briskly blow bubbles into a glass of water through two straws; to make it harder, I blow bubbles with one of the straws out of the water.

To improve my handwriting, which tends to become tiny scrawls, I write notes on 4-line grade school paper.



I May Capitalize Every Word and I usually BLOCK PRINT every important word.

Using an electric typewriter or computer allows for minimum frustration and maximum legibility.

Corresponding with others by exchanges of tape



## *Communicating*

cassette recordings is much easier than writing and most rewarding.

## *Reducing Stress*

The very fact that one is coping with a health challenge increases stress. Therefore, I want to find out how to reduce stress in all aspects of my life. Instead of becoming impatient with myself while doing a routine task like getting dressed, I give myself something beautiful to focus on, like music!

In order not to feel rushed, I make approximate appointments with people, pinning myself down to an exact time only as a last resort.

Because my strength is now more readily depleted and takes longer to recover, I try to schedule a day of rest after one that has been unusually busy. I do need to heed signs of fatigue by taking a nap, which I can do anywhere.

Tension provoking events make coping harder and tremors increase visibly. Although such incidents can cause setbacks, they are fortunately only temporary. Surgery is especially challenging when combined with Parkinson's. Recently I was in the hands of a surgeon and was able to convince him that I would greatly benefit by having my wife at my side. It made all the difference in the world! Instead of being stressed-out, I remained completely relaxed.

Misplacing items is an irritating, stressful event that can be avoided. I place my keys, wallet,

glasses and address book in one designated spot. I attach a long red string to small items, such as a TV remote control, which are easily lost.

Above all, I breathe *deeply*, because tension is reduced when more oxygen is brought to muscle tissue.

### *The Solo Experience*

Circumstance has placed some of us where we must learn to cope alone, without the support of close family or friends. Yet many members of our support group do this well.

If this is your situation, by joining a support group you will come in contact with many people sharing your special challenge. Through a support group one easily learns solutions that took others years of trial and error to develop.

If I were living alone, I would get a dog or a cat. A pet can make one feel needed, protected and understood. A huggable pet could be a real life-saver; a dog's affection is virtually unconditional.

Whenever I go out alone I pay special attention to being well-groomed. At a distance people may be put off by my rigid, wobbly walk. As I get closer they will see that I am clean and clear-minded; that I appear respectable and trustworthy. This could be of vital importance should I unexpectedly need their help.

# C H A P T E R   T H R E E

## *For A Healthy Body*

### *Learning To Listen To One's Body*

*Shifting from "automatic" to "manual" mode with the use of new strategies*

After a good night's sleep my muscles are mercifully relaxed. I work out best when my opposing muscles are still free of tension, so I always do range-of-motion and stretching exercises *before* getting up in order to make the most of this precious daily gift.

Then I sometimes take a "rooted tree" stance and ask my wife to push me from all sides to test my balance. The knees are bent and feet offset, as shown at right.



Frequently I examine my entire body, from head to toe, for needlessly tense muscles. For example, when driving, my left leg should not be "going through the floor board." When my shoulders are dropped from being "up around my ears" from tension, my arms and hands can respond much faster to small corrections required in steering a car.

During the day I often take a moment to notice my reflection in a mirror or a window. I do this to observe whether my posture and facial expression are



## *Learning To Listen To One's Body*

relaxed. I observe the more able side of my body in order to teach the other side how to move.

### ***Deep Breathing***

*An essential skill for body and mind*

Shallow breathing is prevalent not only among those with Parkinson's; most people use only 1/8th of their lung capacity. When I "drink" in air as if it were cool, clear water, my muscles and mood are both nourished by its life giving oxygen.

Of the four organs that excrete body wastes (kidneys, digestive tract, skin and lungs), only the lungs are easily available for conscious control. To reinforce good breathing habits, I do a series of deep, dynamic breaths once every hour, in two stages: first chest and then diaphragm. This purges stale air and oxygenates the deepest, least used recesses of my lungs.

As with many people, I instinctively hold my breath when ready to do something that requires all my strength. This happens to be the exact opposite of what is useful. It deprives my body of oxygen.

My chest muscles used to be so rigid that my breathing was reduced to a survival minimum. Now I am learning to focus on using the diaphragm, fully expanding my chest and inhaling through my nose.

## *Deep Breathing*

*Deep* breathing is the most overlooked, undervalued gift I can give my body and brain.

## *Drinking Water*

Water, like air, is a vital element in our life. It aids kidney function, reduces constipation and even enhances the inner ear's ability to help in balancing. Setting out several cups of water around the house tempts me to drink more.

I drink water mainly between meals, so as not to dilute the digestive enzymes and gastric acids required for best absorption of food during meals.

Saliva protects the teeth. However, some of my medications give me a dry mouth, so I sip water frequently to compensate for the loss of saliva. Chewing on flax seeds, hulled wheat grains, or chewing gum also helps to stimulate saliva flow.

Accidental loss of saliva from the lips is not due to increased saliva production. Rather, it is due to a diminished gag reflex which senses the presence of saliva in the mouth.

## *Walking*

*Building vigor with this total, sustained exercise*

Walking in long strides forces me to swing my arms and twist my body. This torso twisting motion expands and contracts the lungs and subtly massages internal organs, restoring some of the

reduced motility of the digestive tract.

My balance is better when I walk broadly, like a sailor on a pitching ship. Once I actually went on a boat to get the feel for this secure way of striding, arms out to the side for better balance. With a portable tape cassette player playing rousing tunes of marching music I do brisk high stepping, heels-first walking.

When my feet are too painful to go for a walk (in my case due to peripheral neuropathy), I can still get my exercise and a taste of the great outdoors by using a bicycle with training wheels or, preferably, an adult tricycle.

### ***The Swimming Experience***

#### *Graceful, weightless movement*

During each swim I am magically liberated from the ever present burden of gravity. Through the medium of water I am taken back to those care-free years when everything was possible.

While swimming, I aim for powerful strokes and smooth movements. Due to the loss of some buoyant fatty tissue, I now float at a much lower level in the water, making it more of a challenge. This also reduces my margin of safety. Therefore, a good swimmer must be in the water with me or nearby, watching closely.

When swimming in cold water I use a closed-cell



## *The Swimming Experience*

flotation vest or wet suit for warmth and buoyancy. The clarity of goggles gives me confidence, orientation under water, and lets me see if I am using my arms in a full, sweeping motion. By swimming in a lane bordered by buoyant material, I always have a firm support and a place to catch my breath just an arm's length away. Webbed gloves add power to my stroke and help me come up for air.

For me, the water should ideally be around 87 degrees F in order for my muscles to remain relaxed. When it is below 84 degrees I soon become shaky and rigid.

Unfortunately, this form of exercise can not replace walking when it comes to prevention of calcium loss. Only weight bearing impact on the feet can retard osteoporosis in the large bones.

### *Stretching and Range-Of-Motion Exercises*

The typical, constant muscle tension of Parkinson's can be forestalled through stretching, which prevents painful shortening of muscles.<sup>1</sup>

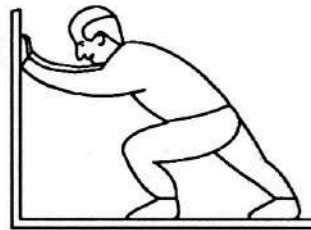
Now I take every possible chance to limber up and strengthen regions of the body, as when I'm on the telephone or watching TV. Tasks like washing the dishes and preparing vegetables, have become finger dexterity games. During lengthy movies, plane trips, dinners or lectures I get up and walk about to stay limber.

<sup>1</sup> See the book *Stretching* (Reference Library, p. 46).

## *Stretching and Range-Of Motion Exercises*

To prevent painful cramps in my calf and thigh muscles I:

- \* Keep my toes pointed towards my knees during my wake-up stretch;
- \* Position my feet so they are not fully extended when I sleep face up or face down;
- \* Stretch the muscles at the back of the legs, one at a time, by leaning forward against a wall without lifting my heel.



In my choice of activities I avoid those requiring sudden bursts of exertion, for they now tend to cause tearing of muscles and tendons. Smooth, diagonal and rotating movements involve the greatest number of muscle groups.

### *Eating*

#### *Nutrition, weight loss and constipation*

I find the Parkinson's experience exhausting, like driving a car with the brakes on. Since I now need far more fuel for the same amount of miles, I require frequent and more nourishing meals.

I have consulted a nutritionist about protein, carbohydrate, and caloric intake. She suggested that I eat mainly unprocessed foods, both for the nutritional benefits and because the roughage aids elimination. She further suggested that I increase my carbohydrate intake with foods like noodles or

## *Eating*

pasta. Some people in our group obtain an increased function from L-dopa medication by not eating protein foods until the last meal of the day.

In order to prevent constipation and the danger of fecal impaction, several times each day I use stool softeners such as prunes, Metamucil<sup>®</sup>, flax, chia seeds or vitamin C powder (in water). This has helped me to avoid becoming dependent on laxative medications.

Burning up calories more rapidly than I did before Parkinson's has prompted me to keep an apple or some dried fruit with me when I'm on the go. This provides a quick pick-me-up if I become dizzy and confused from lack of food.

Since I now eat very slowly, my meals always get cold before I can finish. Popping the plate in a microwave oven can restore the joy of a warm meal. Instead of enduring the balancing act of using a fork, I eat almost everything with a very large soup spoon.

Finger foods are a pleasure to handle. I drink soups from a cup and a special, large diameter straw is useful for thick liquids. I am not ashamed to wear a bib, even in public, and the waiter is always glad to cut up the food for me.

Since swallowing has become trickier, I must not even *think* of talking (and especially laughing) when there is food in my mouth. My ability to sense unswallowed food in the throat is so dimin-



ished that I now swallow twice as often as I used to. This helps avoid jam-ups that might compromise my ability to breathe.

## *Sleep*

### *The pause that renews life*

After a good night's sleep I feel reborn. This can even be true after a short nap.

We sleep on the floor, using a futon, a Japanese, cotton-stuffed mattress. Its firmness makes movement much easier, does not pass on the tossing-and-turning motions of a spring mattress that wake my wife, and is good for the back. Also, by lying on the floor I can't fall out of bed!

We all need to turn over during sleep, but with Parkinson's this is more difficult. The more effort this takes, the more disrupted our normal sleeping pattern becomes. For ease of movement, I've sewn a satin pillowcase to the sheet underneath my torso.

Turning over, as well as the need to empty the bladder, are the main causes of interruption of my sleep. By drinking less in the evening I often can sleep through the night. To void without fully waking up, I use a spill-proof flask. By working daily to keep my arms strong I do not have to be fully awake to turn over.

As people age their sleep requirements diminish. I also meet some of those requirements through

## *Sleep*

momentary naps during the day. So I'm not too worried if I don't sleep very much at night from time to time. I seldom use sleeping pills, only to break a string of sleepless nights that have disrupted my normal pattern.

When I cannot get back to sleep during the night I often listen to the radio (which has buttons to easily pre-select my favorite stations). I use a timer to shut the radio off when I'm likely to have gone back to sleep. Drinking milk and taking a hot water bottle to bed are the old standbys that still work for me.

To help fall asleep or even just relax, I lie on my back and place pillows under my knees and arms (just beyond each elbow). With my eyes closed I think of pleasant scenes and watch them drift past me in a passive, meditative state. Even if I don't fall asleep I always feel refreshed on rising.

## *Relaxation*

The relaxation methods I have benefited from most include: Hatha Yoga, which combines gentle stretching with breathing exercises; T'ai Chi Chuan, a serene ritual movement that encourages good balance and is aptly called "swimming in air"; meditation, which can center and calm a busy mind; Shiatsu, (acupressure massage) which uses a gentle pressure to work out aches and pains; and guided imagery, where by using memories of sound, sight and odors I can transport myself to my favorite Shangri-la.

## *Relaxation*

Progressive relaxation is a method I can use any time, anywhere. Ideally I lie down, slowly tensing and fully relaxing every single muscle from head to toe.

A good calming technique is to place one hand on my upper chest, and the other hand on my diaphragm or abdomen. With eyes closed, I focus on the feeling of warmth that my hands get from my body. Then I alternate this for a few minutes with my body sensing the presence of my hands. I continue this for as long as it brings me to deeper levels of relaxation.

Deep, slow breathing is very calming. By counting to four on every inhalation and exhalation, I focus on my breath rather than any anxiety of the day, and prevent hyperventilation.

Another relaxation method, Tragering, has given me a more limber body, greatly reduced tremors and relieved muscle tension. Developed by Milton Trager, M.D., it is a pleasant experience in which the therapist uses his or her hands to gently move back and forth all parts of the body, helping the mind to let go of all tension. An active part of Trager therapy is called "Mentastics." Tremors seem to melt away as I dangle and swing my arms as if casting off drops of water; walking is done in a knee-lifting, toe-kicking, loose-jointed way.<sup>1</sup>

<sup>1</sup> Trained Trager practitioners are available in many cities and can be located through the Trager Institute, 10 Old Mill Street, Mill Valley, CA 94941.



## C H A P T E R   F O U R

### *Some Closing Thoughts*

#### *Health Care*

##### *Being an active and informed consumer*

My particular health challenge has forced me to learn more about my body, and how it *normally* works. What a fascinating study it is!

One of the most important things I have learned is the sparing use of medications. As we age our organs of excretion become less efficient. Thus medicines are retained longer and may act more strongly than expected. I start using new medications early in the day, when their effects are best observed by me and by others.

Many health problems improve on their own. That is, health may be recovered without aggressive medical intervention. Yet I may want to get relief from intolerable symptoms. This is where being an informed health-care consumer becomes especially important.

To achieve this goal I aim to:

- 1) Have an easygoing working relationship with a general practitioner or internist who keeps my overall health picture in view;

- 2) Find a neurologist who is conservative in his use of medications, has much experience with Parkinson's and treats me as an *individual*. This is crucial because the Parkinson's experience varies greatly in all its manifestations from one person to another, despite the superficial resemblance of posture, tremors, and lack of movement;
- 3) Consult leading experts occasionally;
- 4) Stay on top of the latest research;
- 5) Keep some medical records to establish a history and baseline values useful for future comparison and treatment.

Recently I came to the point of accepting that I could hardly function without my anti-Parkinson's medications. To this extent, life has changed, until something better comes along. I have to schedule my daily routine according to the timing of medications, whereas before I could usually live without such an exact awareness of time.

Although I have become more dependent on medications, life still is under my control. Timing of dosages has to be more exact to avoid falls and "freezing up"—a loss of the ability to move at will. I wear a wrist watch with a beeping countdown timer. Some of my essential medicines are kept in many places, in child-proof vials, so that I can be certain to have them available whenever required.

## *Health Care*

As the cause for Parkinson's is not yet known, relief of symptoms is all that we can presently receive. Fortunately, there are now many promising leads for solving the riddle of Parkinson's. The pace of research has greatly quickened since 1982, when Dr. William Langston's detective work led to the discovery of a neurologic poison (MPTP) which can be used for inducing and studying Parkinson's in animals. This will lead to better treatment of symptoms in humans and possibly even to the reversal and prevention of Parkinson's.

### ***“When Life Has Handed You Lemons, Make Lemonade”***

Many of us go through our adult lives with an image of ourselves as we were in our late teens or early twenties. As I aged, this self-image was only interrupted on occasion, as when I saw my grey-haired reflection in a mirror. But the Parkinson's experience has made that illusion of youth much harder to retain.

It has taken me months and years to absorb and accept the diagnosis. Remaining active in local, national and global issues helps me combat the ever present undertow of depression. I keep my focus off myself through volunteer work at the local hospital. I can also see how fortunate I am with my Parkinson's compared to those I console in the emergency room.

Humans have an incredible capacity to figure out



*“When Life Has Handed You Lemons...”*

how to handle adversity. Even people in continuous pain can overcome their awareness of the pain.

With tapes of music, I have built up sequences to gradually elevate my mood. They carry me back to that “glad-to-be-alive feeling.” I may start with a beautiful, melancholy piece to match my initial mood, such as Samuel Barber’s *Adagio for Strings*. Then I add pieces that will gradually move me from contemplation to joy—for example, the first movement of Brahms’ *Serenade #1*, followed by the third movement of Mendelssohn’s *Symphony #4 (The Italian)*. Finally, I top it off with a burst of ecstasy—“*Gaite Parisienne*” by Jacques Offenbach. The last piece I hear may replay in my head for the whole day!

Rather than reject reality and be ashamed of my tremors, I am learning to accept and even look forward to challenging experiences that may result from being with others. I now feel more comfortable seeing myself in the mirror, as well as allowing others to see me as I am.

By learning to adapt to each change in my range of performance, I maintain a positive outlook, turn back the flood of doubts and move towards a more balanced, fulfilled life. My mind remains focused on the present moment, free to fully experience daily joys and surprises.

A good barometer of my state of mind is whether my thoughts dwell on what I now cannot do, ver-

***“...Make Lemonade!”***

**sus what I *can do*. Whenever I catch myself going down that slippery slope of “I can’t” I aim to give myself a good swift kick—and hop back to the sunny side of the street.**

**It is very uplifting indeed to improve on aspects of my health challenge that *are* clearly reversible. Then I can look the whole world in the eye and, when asked “How are you?” truthfully reply, “In some ways, better than ever!”**

**P.S. New hope is on the horizon! On March 14, 1991, *The New York Times* reported the discovery of a chemical that stimulates and protects the cells that cause Parkinson’s when they cease to function. This chemical substance, called brain derived neurotrophic factor (or BDNF), if developed into a successful treatment, would be the first to actually attack and reverse the Parkinson’s process itself.**

**To Find the Support Group Nearest You Contact:**

**American Parkinson Disease Association  
(APDA)**

800-223-2732  
apda@apdaparkinson.org  
apdaparkinson.org  
PO Box 61420  
Staten Island, NY 10306

**The Parkinson's Foundation**

800-473-4636  
Helpline@Parkinson.org  
parkinson.org  
200 SE 1st Street, Ste 800, Miami, FL 33131  
or  
1359 Broadway, Ste 1509, New York, NY 10018

**(also ask to be put on their mailing lists  
for their very helpful, free newsletters)**



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**“Helix” polished stainless steel  
Storm King Art Center, NY  
Sculptor: Jan Peter Stern**



## About the Author:

Born in Europe, Jan Peter Stern (1926-2004) came to the United States in 1938. After his military service (U.S. Army 1945-46), he attended Syracuse University and in 1953 received his B.F.A. degree in Industrial Design.

Mr. Stern worked from 1953 to 1958 as a product design engineer, and then embarked on a successful career as a sculptor. His work now graces many public plazas and can be found in museums and private collections across this country and abroad.

The motivation for this booklet lies in Mr. Stern's lifelong dedication to helping others: he was a member of the National Ski Patrol for many years, has taught First Aid for the American Red Cross since 1948 (and CPR more recently), completed training as an Emergency Medical Technician, and works as a volunteer in the Department of Emergency Medicine at the University of California at Los Angeles since 1981.

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### Some Comments About This Booklet:

*"It's a masterpiece. You have packed more useful information into [these] pages than some of us have in full length books. I feel a kinship to you... Congratulations on a major contribution to the welfare of Parkinsonians."*

Sid Dorros, author of *"Parkinson's, A Patient's View"*

*"Only someone that actually has P.D. and has experienced the many problems that affect our daily lives can cover the subject as well as you have... An outstanding contribution... Everyone with P.D. should read your book."*

Leonard Burgess, M.D., Orthopedic Surgeon and veteran Parkinson's fighter, Santa Barbara, CA

*"I have never before seen such an inspiring, uplifting, positive approach to coping with Parkinson's...to have it put in book form is of tremendous benefit to our members."*

Jan Hansen, Support Services Director for the Parkinson's Society of Southern Alberta, Canada

*"Rich with good ideas for daily living. Excellent!"*

Professor Leo Treciokas, M.D., Neurologist specializing in the treatment of Parkinson's at UCLA and in private practice

*"I found your Parkinson's Challenge booklet wonderful reading... Your insights and expressions of them are penetrating. Your metaphors are exceptionally well conceived... This responsible booklet is something all P.D. persons can cherish."*

Devra Breslow, Director of "Art that Heals Program," Jonsson Cancer Center, UCLA