

COPE WITH HOPE

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When I was diagnosed with Parkinson's disease in 1985, I realized that living with a "progressive" disease was going to require continuing adjustments and accommodations through the years and that the word "*cope*" would hold new importance in my vocabulary. I also recognized that the decision as to *how* I would cope was mine, as it is yours. I chose to focus on the positive. Life is certainly more difficult for me today, but whatever the circumstances, I still feel a smile and a positive attitude make it easier to face the future. I'm not suggesting a "don't worry, be happy" attitude; but life should be looked at as an adventure to be lived rather than a problem to be solved. Perhaps some of the following suggestions will be helpful.

Concentrate on the positive. You may not have the ability to change what is happening to you, but you *can* change how you relate to it. People generally find what they expect to find. If you expect to feel bad, your body won't disappoint you. You will feel bad. If you expect to feel good, there's a greater possibility you *will* feel good. Also examine the stories you tell yourself (and others) about your illness. It is easier for family and friends to offer support to someone with an optimistic attitude.

Parkinson's has been described as a "yo-yo" disorder...one hour up, the next down; one day good, the next bad. It helps to remember that one bad day is only one bad day. It does not constitute a trend. Assume tomorrow will be better. Your mind can help heal your body when bolstered by hope and expectation according to studies on the "placebo response." Better symptom control lies not only with pills or surgery, but with ourselves as well.

Acceptance. Parkinson's is just something I have...like brown eyes; so I refuse being referred to as a "patient" unless I'm in a doctor's office. Acceptance...does not mean you need consider yourself "sick." Unlike having a headache though, Parkinson's can be difficult to hide. It's easier not to try. Be open with others. I have found that people are interested in learning about the disease and are appreciative that you shared the information. Rather than think of Parkinson's as a problem, consider it a situation, a challenge, an opportunity. You will be less anxious, less frustrated and less stressed, which will result in fewer symptoms.

Become informed. Knowledge is the first positive step toward being in control. Be responsible for your own health care. You know your body best. It's vitally important to read everything you can find! Visit your library, request to be put on mailing lists for newsletters and medical updates, use the Internet and attend lectures. You'll better understand why symptoms occur which will allow you to know what questions to ask and how to properly describe the problem when you see your physician. Find a doctor who has knowledge and experience in treating people with Parkinson's. One who is interested, patient, understanding, cooperative and willing to take the time to work with you. Your pharmacist is another good resource for information. Join a support group for valuable, shared, personal advice and support.

Set achievable goals. You may need to set new and more achievable goals because of the limitations Parkinson's has placed on you. It's important to learn to pace yourself. When adapting to a less active schedule, there is a tendency to overdo when you feel good. After a busy period, schedule activities that don't require a lot of energy. Have an alternative in case your symptoms require you to cancel a planned event. Planning ahead gives you the flexibility to accomplish things when you feel good. For instance, you can shop in advance for birthday and anniversary presents. Address cards ahead of time.

Keep a sense of humor. Laugh at yourself. A laugh a day is more important than an apple in keeping the doctor away. When a chuckle would feel good, go to the closest drug store or card shop and tickle your funny bone by reading greeting cards. A laugh is much better for your immune system than getting angry or frustrated.

Simplify your life. Learn to say “no” without feeling guilty. Find easier ways to do things. Determine your priorities. Eliminate the unnecessary.

- † Call stores to make sure they have the item you need.
- † Shop during off-hours to avoid crowds and lines.
- † Get a disabled parking permit.
- † Use stores that deliver or have drive-up facilities.
- † Use a cordless telephone; keep a telephone by your bed; consider an automatic dialer and/or a speaker phone.
- † Always carry extra medication with you. Get a sports bottle to have water for taking pills.
- † Keep a written schedule of your medication. Buy a pill container that has a weeks worth of dividers. This saves time and identifies if you’ve taken a particular dose.
- † Get a timer to remind you when medication is due.
- † Use stick-on labels or a pre-inked rubber stamp when you need to write your name or fill out forms.

Keep active. Exercise, both mental and physical, is essential in maintaining your lifestyle. It prevents your muscles from deteriorating, strengthens them, reduces tension and rigidity, improves your ability to rest and sleep and enhances other bodily functions. Walking is one of the best exercises. Choose activities that let you play. Take dancing lessons or enjoy some of the less strenuous sports such as golf, tai chi, bowling, horseshoes or swimming. The more active you are, the longer it will be before you need physical, occupational or speech therapy. Exercise *can* be fun and HAPS offers many of these options.

It’s also important to keep active socially. Don’t allow yourself to become isolated. Participate in our support groups to meet new people, develop new friendships and help avoid depression. Instead of focusing on yourself, help someone in need. It will get your mind off of yourself and you’ll remember how much you have to be thankful for.

Have faith and never give up hope. Reflect on the wonderful attitude of Charles Murray who wrote to the Parkinson’s list on the internet: “The way I look at it, living with PD is a bit like venturing into the Himalayas while most of our brothers and sisters travel less rugged slopes. We can grumble about how steep and hazardous the climb...preoccupied with the expense of our climbing gear, the physical exhaustion and the fear as the slopes turn into shear walls of granite. Or, we can live in the moment and focus on appreciating the spectacular beauty found only in such imposing terrain. No one can take this choice from us.”

Have faith that with all the research being done, the hope of finding a cure appears closer than ever. Actively working to help” find the cure” (by being an advocate) helps give me courage and energy. I invite you to join me in working toward that day.