



HAPS HAPPENINGS

OCTOBER 2005

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~ OCTOBER IS CAREGIVERS MONTH ~

Caring for the Caregiver



There is pride and gratification in caring for a chronically ill, disabled family member or someone with whom you have a personal relationship, but the role of a caregiver/care partner is not an easy one. Although there are physical, psychological, emotional, social, and financial stressors associated with the caregiving experience, your perception of your responsibility will determine the impact it has on your life. You may even discover reserves and resources you didn't know you had.

Hope and fight for the best but prepare and plan for the worst. Preparation doesn't mean that you should dwell on the worst aspects. That can be all consuming and doesn't help. However, the disease may eventually intrude upon your life making you thankful that you considered your alternatives and prepared early.

Coping with the multiple problems of a complex disease is not easy. Try to maintain a "normal" life and continue to work to beat the disease – but realize you may need to redefine and create your own "normal" within the boundaries Parkinson's has set up.

Changes in your lifestyle are inevitable.

When your day is filled with "caregiver" acts of love such as preparing a meal, giving a bath and toileting, grains of resentment, isolation, or sadness may rub at the bonds of your commitment, particularly if you allow yourself to become an extension of your care partner's illness. It would be unrealistic to suggest that you won't have periods of sadness, emotional paralysis and inaction but thinking clearly, taking action, and making changes when necessary will help you maintain some sense of equilibrium and control.

Realize that some days may take every ounce of strength and determination you have to confront the challenges of the day, but keep in mind that some days will be better than others.

Since there *is* some uncertainty about what each day will bring, it is not uncommon to feel a lack of control over your life. You will feel more in control if you take time for yourself; although in reality, none of us are really in control of what happens in our lives (we just like to think that we are.) In any case, whatever positive steps you can take to cope for your own survival as an individual should be a priority.

Caring for the Caregiver continued

So, how do you keep "well" in a world that is not so well? Start thinking of your life in two parts; the first part as a caregiver; the second part as your own.

- ☺ **Hesitate a bit before you jump in to help.** As the disease progresses and mobility is restricted, you may find yourself doing “too much” in an effort to be helpful. It’s important to allow your loved one to do as much as he or she feels capable of doing safely. This will not only maintain his or her self-esteem but will be less demanding on your time.
- ☺ **Get as much help as you can** (or can afford).
- ☺ **Be assertive.** Let family and friends know how you feel and how they can help you.
- ☺ **Learn to manage stress.** Try deep breathing exercises, meditation, biofeedback, etc. to release the tension.
- ☺ **Be flexible.** When roles and responsibilities change, be flexible in deciding what each of you can do.
- ☺ **Exercise.** Come to HAPS exercise groups where you can enjoy the camaraderie and participate together. Let a walk outdoors give you spiritual and mental strength.
- ☺ **Give yourself permission to cry** and vent your feelings, but avoid "pity parties."
- ☺ **Make a “gratitude list”** of all the things that you are grateful for in your present situation.
- ☺ **Take time away to feel “normal.”** You will come home refreshed and able to do what you have to do.
- ☺ **Do things you can still enjoy doing together.**
- ☺ **Develop a sense of humor** about humorless circumstances.
- ☺ **Get enough rest.** Tempers get short and patience wears thin when you are tired.
- ☺ **Eat properly.** Good nutrition gives you energy you need.
- ☺ **Give yourself permission to procrastinate.** If the thought of all the tasks that need to be done seem overwhelming, give yourself permission to take some time off.
- ☺ **Be good to yourself.** Be selfish with your free time. Build things into your week that you enjoy. Pursue hobbies and interests and continue to grow. Keep a journal, play with your grandchildren, write letters, garden, pray, meditate, read a good book. Treat yourself to a special lunch out, time with friends, a manicure, a movie, or do some volunteer work. Maintain your own interests or develop new ones that have nothing to do with Parkinson’s disease.
- ☺ **Communicate.** Accept your frustration. Discuss your concerns and don’t keep them bottled up. Talk about your feelings with the person you are caring for, a close friend or someone else who has Parkinson’s in their life.
- ☺ **Seek help.** Go to support groups. Almost everyone experiences the feeling of desertion and may cope by withdrawing. Reach out instead. Connect. You are not alone unless you isolate yourself. It is comforting to know there are others who share your experiences and feelings of loneliness, grief, depression, anxiety, dullness, fatigue, lack of appetite and lack of freedom. Take advantage of the caregiver support groups that HAPS offers that are led by Kathleen Crist, LMSW, HAPS Director of Social Services.

Caregiving was not meant to be the only thing you do in life. Remember that you don’t have the disease and your care partner should want you to have a life as well.

Your Key to Good Health



TAKE CARE with the MedicAlert E-HealthKey



With an estimated 100,000 deaths each year as a result of medical errors, it makes good sense to take every precaution available. In a medical emergency, things happen fast. Health care providers need a simple way to get information.

You are probably already aware that one call to MedicAlert® provides your vital medical information, including medications, dosages, and details about implant and medical devices, notifies your family and provides identification if you are unconscious or confused.


Now, something new. You can carry your complete personal health record with you at all times. Emergency information is available from the new MedicAlert® E-HealthKey which can be plugged into any USB-enabled computer. The MedicAlert® E-HealthKey also enables patients to manage other health and wellness information such as tracking and trending labs, immunizations, storing images (like x-rays) and receiving automatic reminders. Patients will also have the opportunity in some instances to link personalized content and educational resources from MedicAlert® partners.


The MedicAlert® E-HealthKey will be instantly recognizable by medical personnel and first responders. The MedicAlert® E-HealthKey detects when it is plugged into the "home" computer or into an unknown computer. If plugged into an unknown computer, the E-HealthKey assumes that it is being inserted into a computer of an Emergency Room (ER) or an ambulance. The application will immediately pull up and present only the critical medical information such as condition, allergies, etc. that the patient/member has previously authorized. In addition to the E-HealthKey, clinicians also have access to a patient's medical record via the MedicAlert® 24/7 contact center enabling instant responses - even internationally.





- Protects from being given the wrong drugs in an emergency
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- Ensures that patient won't be alone in an emergency
- Ensures medical information remains confidential
- Prevents unnecessary or repeat tests

Take good care of yourself and learn more about this useful tool. Someone who cares will answer the call at the MedicAlert® 24-Hour Response Center. Call toll-free any time and speak with a trained Member Service Associate. 1 (888)ALERT90 - 1 (888)253-7890 www.medicalert.org



 You're getting old when "tying one on" means fastening your MedicAlert bracelet.

 Ever stop to think, and forget to start again?

 "Don't worry about the world coming to an end today. It's already tomorrow in Australia." Charles

To Share With Those Who Care...

Joan Blessington Snyder is 54 years old, has had Parkinson's for 14 years and is active with the Parkinson's Action Network. I have excerpted parts of a speech she gave at a dinner honoring Congressman Lane Evans. I share this with you because I am frequently asked to write something that you can share with others to explain what Parkinson's is like, and I couldn't do a better job than Joan has done. But I also share it with the hope that you will realize that you have the choice to follow the examples set by Joan and Congressman Evans to handle the challenges that Parkinson's presents.
Your editor

There is good news and there is bad news to report about Parkinson's disease. The good news is that doesn't kill you. The bad news is that it doesn't kill you.

Parkinson's disease takes no prisoners and it doesn't care who or what you are. It is THE great leveler. It has held hostage Pope, evangelist, artist, attorney general, actor, congressman, the world's greatest...and mere mortals such as me.

It is a robber disease. It comes like a thief in the night and steals away parts of your personality, your self assurance and your ability to do everyday tasks with ease. It shows no mercy.

I find it to be extremely telling that people line up to endure a brain surgery called DBS during which they must be wide awake and conscious for the 8-10 hours that the procedure lasts. They allow doctors to insert wires into their brain and run those wires down the skull and attach them to implants in their chest so that they can be fine-tuned and electronically manipulate their symptoms... all of this rather than to continue to live with this damn, debilitating, disease.

For a moment, I invite you into our world. Every morning, pain and stiffness awaken us. The pain does not dissipate eventually like a hangover, but becomes a dull, tedious thing that you wear always, like a heavy coat. More important tasks then consume your energy...like walking, talking, eating--you know, ordinary stuff like that! You do them mostly by rote, knowing how stiff your gait will be and compensating for that by arriving early. You know how soft your voice will be at certain times of the day, so you plan your good times when the medicine is working to do your business...and you know that everyone is watching you: waiting for you to slop your soup or to drop something or to fall. They watch because they care but they cannot understand. My children become exasperated with me and say, "Just move your foot, Mom." I tell them that if I could do that then I wouldn't have Parkinson's disease.

Most Parkinsonians are over-achievers. We must overcome that nagging little voice that whispers "*you cannot change the world or the course of my impact on your soul and your personality.*" "*Here, stay inside and hide*" it whispers. "*It is better to be alone, let me have my way with you, don't try to do anything to defeat me, don't let anyone see what I can do to you.*"

Now, there are people with Parkinson's disease, who stand up to that little whisper. They do not let it take control of their lives; people with the bravery and leadership to grab this bull by the horns and demand that their voices be heard over the whispers of the "tyrant" PD. Lane Evans is one of those people.

I am proud to know a man who each and every day of his life, lives the words spoken by Pope John XXIII:

"Consult not your fears
but your hopes and your dreams.
Think not about your frustrations,
but about your unfulfilled potential.
Concern yourself not with what you
tried and failed in, but with what
it is still possible for you to do."

CONTRIBUTIONS

Your donation is much appreciated. Your thoughtfulness helps help continue to provide much needed services to people with Parkinson's and their families.

Gifts

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Your donations are tax deductible

PARKINSON'S and STEM CELL RESEARCH

It was recently announced that scientists in Edinburgh have been able to grow and sustain pure brain cells. The long-term aim of this breakthrough research is that the cells will be used to build replacement neural tissue for Parkinson's and Alzheimer's.

Come learn more about stem cells. Mark your calendars to attend a 30 minute Power Point Presentation.

Stem Cell Research: The Science, Ethics and Politics

Presented by Nina and Joe Brown

Thursday, November 10, 2005

11:15 a.m.-12:00 noon

2700 Southwest Freeway

RSVP: 713-218-8888

HAPS HAPPENINGS

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