



PARKINSON UPDATE

PARKINSON FOUNDATION OF THE HEARTLAND



WINTER 2004

Optimizing Wellness During The Coming Holiday Season

For many of us, the holidays are a time to gather with friends or family, celebrate, reflect on the past and plan for the future. However, for some, particularly those of us with Parkinson's disease, the holidays can be a difficult time. As we age, we tend to feel the passing of time more acutely, notice the absence of parents and other loved ones, and mourn holiday rituals and celebrations that are no longer possible. Many people find that the holidays, and in fact, winter, exacerbate symptoms and make our dreams of living independently and with dignity seem more remote.

Many factors contribute to the holiday blues: stress, fatigue, unrealistic expectations, over-commercialization, financial constraints and the inability to be with one's family and friends. While we can't blame Parkinson's disease for the commercialization of the season, we certainly can draw direct connections between PD and stress, fatigue, financial constraints and time lost with loved ones. What to do? Decide for yourself what the holiday means to you and how you are going to make

it a positive event. We must all adjust our expectations to match our current reality. Try to set realistic goals for yourself.



Pace yourself. Organize your time. Make a list and prioritize. Be realistic about what you can and cannot do.

Remember that we are here to provide resources and information, or just a listening ear. Each of you is an inspiration and special gift to all of us here.

Don't put the entire focus on just one day, remember it is a season of holiday sentiment and activities can

be spread out to lessen stress and increase enjoyment. Reach out and make new friends or contact someone you have not heard from in awhile. Keep hope alive. Remember that life brings change. Each season is different and can be enjoyed in its own way.

In this issue of the Update, you will learn ways to plan ahead to make the most of the coming season, tips for keeping safe, lowering your stress levels, dealing with grief, and optimizing your wellness through nutrition and exercise. We have included special articles for caregivers who may find the coming months to be particularly stressful.

All of us at the Parkinson Foundation wish you a joyful and hope-filled holiday season, and extend our sincere wish that Santa brings you a big bag of dopamine this year! Remember that we are here to provide resources and information, or just a listening ear. Bless you all for your strength, dignity and perseverance in the face of adversity. Each of you is an inspiration and special gift to all of us here.

PRESIDENT'S MESSAGE



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Hello All!

Can you believe we are about to commence with the Holiday seasons of Thanksgiving, Hanukkah and Christmas? Time is flying by, so we better enjoy our time. This has always been my favorite time of the year because people seem to be in such good moods. I know there are many hardships both physical and emotional that go along with Parkinson's disease (PD), but I implore everyone to reach out to your family and friends during this holiday season and know that many people are working hard to ease the pain and debilitation of PD. Enjoy and love, especially during these next two months, and know that all people connected with the Parkinson Foundation of the Heartland are anxious to improve the quality of life for people with Parkinson's.

Happy Holidays!

Bob
Bob Kennedy
President



Safe Holiday Decorating Tips

Do you know that each year hospitals treat over 200,000 people for falls, cuts and shocks related to holiday decorations? Decorating can be a fun and festive way to celebrate the season, and with a few simple tips, can be easy and safe for everyone!

- We all get used to a routine and layout, and changes in the household walking paths can lead to falls. Try not to put any decorations in common walk areas. Avoid rearranging your furniture to accommodate decorations, particularly if someone in your house has any problems with their vision.
- Remember that Parkinson medications can affect balance and coordination. Leave plenty of room in pathways, and be sure that decorations are placed so that people do not fall on sharp or protruding objects.
- Be sure that outdoor decorations are well away from pathways and do not block light. Be sure that decorations do not block views from the front door or driveway. Make sure that outdoor decorations are secure and will not become wind borne.
- Choose holiday decorations that are flame-resistant, flame-retardant, or non-combustible. Keep candles in sturdy holders and don't place them where they can be knocked to the floor or into other decorative items.

- If you choose a live tree, be sure that it is fresh, keep it watered, and place it well away from heat sources such as fireplaces, space heaters or radiators.
- Carefully inspect new and used light strings and replace any damaged parts before you plug them in. Don't overload extension cords.
- Always unplug lights and extension cords before leaving the house or going to bed.



Caregivers and Seasonal Stress

Our many wonderful caregivers can have a more peaceful and joyful holiday season by learning to cope with the additional stress that comes with the season. During the holidays, caregivers can feel guilty and frustrated because they think they're not doing enough and they miss being able to do those things that once made the holiday so special. During this time of year, there are more things to get done, and often a greater sense of loss of the things you and your partner used to do.

Studies show that the majority of those who provide major care for their partners experience stress. This is a serious concern because prolonged stress can have serious physical and emotional consequences. When you are caring for others, taking care of yourself and your needs is essential to being able to provide care over time. There are things you can do to nurture yourself and cope with stress.

TAKE CARE OF YOUR HEALTH!

Enjoy holiday treats, but don't give into stress-driven urges for lots of sweets. Try to eat nutritious meals. The Parkinson Foundation has many recipes for special diets, including diets low in protein, salt, or that are easy to chew and swallow.

GET ENOUGH SLEEP.

If you are awakened at night, try napping during the day to make up for your loss of sleep.

EXERCISE REGULARLY.

Try to find someone to exercise with – it will keep you going. Call the Parkinson Foundation to receive your free copy of Motivating Moves for People with Parkinson's.

TREAT DEPRESSION.

If you have any symptoms of depression, see a doctor right away. Depression is an illness that can be treated. For seasonal "blues," buy an indoor light box with at least 10,000 Lux of natural full spectrum lighting. Most people use a light box for 30 – 60 minutes each day. Check with your doctor before using a light box, particularly if you have any type of eye problems involving the retina, especially macular degeneration, retinitis, pigmentosa, and diabetic retinopathy.

MAINTAIN OR ESTABLISH SOCIAL CONTACTS.

Isolation increases stress, while having fun, laughing, and focusing on something besides your problems can help you keep your emotional balance. Try to plan at least three social activities each month. This helps you and ultimately makes you a better caregiver.

CALL ON YOUR FRIENDS AND RELATIVES FOR HELP.

Make a list of tasks you need help with and ask friends and relatives if they would contribute regularly or even occasionally. List out tasks that need to

be done everyday, every week, once a month or seasonally.

USE COMMUNITY RESOURCES.

There are many community resources to help you, such as the Parkinson Foundation, geriatric care managers, meal and shopping services, information and referral services, and volunteers from faith-based organizations or civic groups. Call us and let us connect you with the resources you need.

TRY TO FIND TIME FOR YOURSELF TO UNWIND WHEN STRESSES PILE UP.

Do something you enjoy such as reading, walking, or listening to music. Some people find it helps to meditate or use relaxation techniques, such as deep breathing or visualizing being somewhere that makes you feel calm. The Parkinson Foundation has audio and video relaxation tapes available, and autogenic relaxation training available at our Wellness Center.

ORGANIZE AS MUCH AS YOU CAN.

Make a list of what needs to be done and get the most important things done first. Pace yourself, don't overwork yourself to the point of exhaustion. Set limits. Caregivers need to learn to say no.

Fighting the Holiday Blues – (Any Time of Year)

Depression can strike anyone at anytime, but people with Parkinson's disease seem to be more likely to suffer its effects. The stress associated with the coming season may stir feelings of loss and separation, placing the Parkinson patient at even greater risk for a depressive episode. Treatment for depression helps people manage both diseases, thus improving the quality of their lives. Please watch for the signs of depression and seek help!

The most common symptoms of depression are:

- Persistent sad, anxious, or “empty” mood
- Feelings of hopelessness or pessimism
- Feelings of guilt, worthlessness, or helplessness
- Loss of interest or pleasure in hobbies and activities that were once enjoyed
- Decreased energy, fatigue, feeling “slowed down”
- Difficulty concentrating, remembering, making decisions
- Insomnia, early-morning awakening, or oversleeping
- Appetite and/or weight changes
- Thoughts of death or suicide, or suicide attempts
- Restlessness, irritability

People with Parkinson's, their families and friends, and even their physicians may misinterpret depression's warning signs, mistaking them for the inevitable accompaniments to Parkinson's disease. Symptoms of depression may overlap with those of Parkinson's and other physical illnesses. However, skilled health professionals will recognize the symptoms, diagnose the disorder, and suggest appropriate treatment. A person who may be depressed should see a medical professional – a family doctor, a general psychiatrist or a psychiatrist specializing in neurology or geriatrics. Always be sure that your neurologist is informed of any treatments for depression or anxiety. This is especially important when antidepressant medication is needed or prescribed, so that potentially harmful drug interactions can be avoided.

Use of herbal supplements of any kind should be discussed with a physician before they are tried. Recently, scientists have discovered that St. John's wort, an herbal remedy sold over-the-counter and promoted as a treatment for mild depression, can have harmful interactions with some other medications.

Sometimes the hardest part in helping someone who is depressed is finding an approach that does not contribute to his or her feelings of defensiveness, sadness or helplessness. If you are at a loss for words, you may want to consider some of the following ways to begin:

- **Discuss your own varied feelings or a time in your life when you were depressed. Knowing that you understand may give them permission to talk about their own feelings.**
- **Acknowledge that the holidays can be difficult, and that the past several months/years have been hard on everyone. Many people don't want to admit that life is not always cheerful.**
- **If the person is not eating or has lost weight, you might start by gently asking about their appetite.**
- **Once you have gotten past the initial awkwardness, you may be surprised to learn that your loved one is anxious to talk. At that point, listen and offer support.**
- **Offer specific suggestions for help and be willing to assist in implementing them.**

Recovery from depression takes time. Medications for depression can take several weeks to work and may need to be combined with ongoing psychotherapy. Not everyone responds to treatment in the same way. Prescriptions and dosing may need to be adjusted. No matter how advanced the Parkinson's disease, however, the person does not have to suffer from depression. Treatment can be effective!

Other mental disorders, such as bipolar disorder and anxiety disorders, may occur

in people with Parkinson's, and they too can be effectively treated. However, some Parkinson's medications may worsen mania in persons with co-occurring bipolar disorder. The prevalence of bipolar disorder among individuals with Parkinson's disease is unknown, but people in treatment for PD should be alert for symptoms of bipolar disorder. Bipolar disorder is characterized by intense mood swings and changes in behavior.

It may take more than one conversation and more than one day or one week to get the individual to agree to get help. If they are struggling with depression, they may not want to hear what you have to say and may resist your suggestions. Be persistent. This is a difficult process for all involved, but knowing that depression is treatable makes it easier to address.

For many people, there may be a stigma attached to asking for help and to having any discussion of depression or mental illness. Part of your role is letting them know that depression is treatable and life will get better.

Many families rely on nursing homes to provide the consistent care needed for Parkinson's disease. Depression can arise when individuals are in nursing homes or other long-term care situations. The holidays may be especially hard on these individuals because of the loss of their independence and mobility.

If your loved one is in a care facility and you suspect that he or she is depressed, you may want to talk with the nursing home administrator or director of nursing about the symptoms you notice. You may want to request a consultation with a physician or psychiatrist. If the individual is in frail health, you need to be certain that the doctor is trained in caring for the mental health of the frail elderly whose ability to tolerate treatments may be different.

• Ask whether the facility provides physical and social activities for the residents. We all need exercise and social interaction.

Fighting the Blues...CONTINUED

- Ask about the qualifications of staff professionals monitoring care, especially regarding the dispensing of medications.
- Ask specifically about mental health care, including access to group therapy.
- Ask about the availability of psychiatric care through a staff or affiliated psychiatrist.

Remember that all patients should have access to the care they need – physical and mental- regardless of the setting. Insist that you or your loved one receives appropriate treatment.

Beat the holiday blues by attending our Christmas Party! Details on back cover!

Depression Self Assessment

- 1. Do you have any first-degree relatives (parent, siblings) with a history of depression?**
 1. yes
 2. no
- 2. Which of the following best describes your general mood?**
 1. I feel sad some of the time
 2. I feel sad most of the time
 3. I feel sad all of the time
- 3. Which of the following best describes your feeling about the future?**
 1. I am sometimes discouraged about the future
 2. I am very discouraged about the future
 3. I feel that the future is hopeless
- 4. Which of the following best describes your feelings about your accomplishments?**
 1. I sometimes feel like a failure
 2. I feel like a failure more often than not
 3. I feel like a failure all of the time
- 5. Compared to the past, do you still enjoy activities and hobbies now?**
 1. I don't seem to enjoy things as much as I did in the past
 2. I rarely seem to enjoy things as much as I did in the past
 3. I don't enjoy things the way I used to
- 6. Do you feel that you are a useful and needed person?**
 1. I sometimes feel useless and not needed
 2. I feel useless most of the time
 3. I feel useless all of the time
- 7. Do you feel happy with yourself?**
 1. I sometimes dislike myself
 2. I mostly dislike myself
 3. I hate myself
- 8. Do you have unexplained crying spells?**
 1. Sometimes
 2. Often
 3. I cry all the time
- 9. Do you feel more irritable now than in the past?**
 1. I sometimes get irritated more easily than before
 2. I get irritated more frequently now
 3. I am irritated all the time
- 10. Have you noticed any weight loss or gain?**
 1. Less than 5 lbs
 2. 5-10 lbs
 3. More than 10 lbs
- 11. How would you describe your energy level?**
 1. I sometimes have difficulty concentrating
 2. I frequently have difficulty concentration
 3. I'm too tired to do much of anything
- 12. How would you describe you ability to make decisions?**
 1. I have some trouble making decisions
 2. I frequently have trouble making decisions
 3. I always have trouble making decisions
- 13. Do you ever have thoughts of harming yourself or suicide?**
 1. I sometimes have thoughts but would not act on them
 2. I fell I'd be better off dead
 3. I have a plan to commit suicide

If your answers to 6 or more questions are 2's or 3's, you are likely experiencing some depression. People with Parkinson's disease are prone to depression – but don't have to feel that way. See a medical professional – your family physician, psychiatrist or neuro-psychiatrist or your neurologist. Always inform your neurologist of any treatments for depression or anxiety. This is especially important when antidepressant medication is needed or prescribed, so that potentially harmful drug interactions can be avoided.

Grief and The Holidays

So many of us have lost loved ones to Parkinson's, which can be such a cruel and unforgiving disease. Wives, husbands, sons, daughters, brothers and sisters, girlfriends, boyfriends, friends and neighbors; we are all united in our fight, our pain, and our hope.

For many, this will be a holiday season of loss: loss of long-held partnerships, loss of deeply held love, loss of our "touch-stones" and our friends. The holidays bring a new height of suffering for those of us struggling with the loss of our loved ones.

■ **Plan ahead.** Don't allow the holidays to simply happen. Decide what makes you comfortable and go with that. Plan ahead for the best event for you!

■ **Perform at your ability.** Accept your limitations and don't beat yourself up for not having the holiday event you think you "ought" to have.

■ **Create a new holiday ritual.** If specific traditions or rites are too painful, leave them out this year. Add something new.

■ **Ask for help.** Reach out to others for help shopping, cooking or wrapping. Come to the Parkinson Foundation for a meal, an ear, or a friend.

■ **Vocalize your needs.** Tell your friends, your family, your church, or us that you are struggling. Be specific about your needs.

■ **Be human!** You may assume that things will be fine, and suddenly feel pain and sadness. Let the tears come and the grief flow. Shift plans if you need to. Cancel plans, stay home, watch a movie, cry, sleep, listen to yourself.

■ **Memorialize your loved one.** Make a donation, do a good deed, or just spend time in contemplation. Make the moment count.

■ **Talk about the deceased.** It's healthy and normal to tell stories and remember times with your loved one.

■ **Keep good company.** Choose to be around people that make you feel safe and happy. Make sure you are comfortable.

■ **Be wary of quick fixes.** Watch your intake of alcohol, sweets, and your shopping habits.

■ **Be gentle with yourself.** Love yourself as you were loved and as you have loved.

If you are suffering, remember that you are working with less physical and emotional energy than most. Allow yourself room to grieve and time to heal your wounds.

Tips for A Good Night's Sleep

Abnormal sleepiness occurs in about fifty (50) percent of PD patients. Any of the dopamine medications can potentially cause daytime sleepiness or episodes of unintended sleep. Excessive daytime sleepiness can be caused by medications, depression, insomnia, or other sleep disorders. A careful review of all current medications is important. Sleep problems can be managed through the use of good sleep habits.

■ **When you lay down to sleep,** deepen and lengthen your breathing patterns. Try for five second inhales and five second exhales. At this rate, you will be taking about six breaths per minute. This takes some practice, but is very efficacious.

■ **Take a deep breath and hold it.** While holding your breath, tense the muscles in your entire body and hold both for 30 seconds. Exhale and relax. Repeat several times.

■ **Make sure your bedroom is dark.**



■ **Exercise regularly.** Exercise does a fantastic job of regulating sleep cycles, but don't exercise within two hours of bedtime, as this can activate mind and body systems that might keep you awake.

■ **Take a hot shower or bath before you go to bed,** or get up and do so if you are unable to fall asleep within fifteen minutes.

■ **Take some "sleep food" before you go to bed.** Eat one ounce of protein, one ounce of cheese, or five grapes.

■ **Get out of bed if you are not asleep within 20 minutes.** Don't let the brain associate "bed" with "awake." Once out of bed, don't turn on the TV, lights or use your computer. Sit quietly, meditate, and concentrate on emptying your mind.

■ **If you can't sleep, consult your doctor.** There are some wonderful medications to help you sleep that are non-addictive, work well with Parkinson medications, and will leave you feeling refreshed and positive in the morning.

Nutrition During the Holiday Season

Throughout the year, people with Parkinson's disease must eat a carefully planned and balanced diet to ensure they keep their weight up, their bones healthy, stay fully hydrated, keep their bowels moving and maximize the effects of their medications. This can be difficult during normal times, but the holidays pose special challenges.

Your optimal diet is reasonably low in fat and protein, and high in fiber and fluids. Calcium and B vitamins are also very important for bone health and to combat dizziness, depression, memory loss and mood swings. Calcium is found in cheese and fortified milk, though these are high protein foods and may interfere with the absorption of levodopa. Good choices for calcium include fortified orange juice, calcium fortified rice or soy milk, and fortified breakfast cereals. You can also take a calcium supplement or chewable tablet.

The B-Vitamins include thiamin, riboflavin, niacin, pyridoxine, folate, biotin and pantothenic acid. The B-vitamins are found in whole grains, vegetables and fruits, dairy, dried beans, fish, poultry, eggs, and meat.

Be sure that you drink at least four glasses of water per day, in addition to juices and other beverages. Parkinson's medications can raise the risk for dehydration. Fluids also help aid bowel movements and help you avoid constipation.

Many people with Parkinson's disease experience cravings for sweets and sugar. While sweets don't interfere with the absorption of Sinemet, they do contribute to constipation and elevated blood sugar. Candies, cookies and other sweets are everywhere this time of year! Be vigilant and work to control your intake of sugars.

Many of us will attend holiday parties with buffet style meals. These types of meals can make it very easy to eat too much protein and sugar. Choose only one ounce of protein, this would be a serving about

1/3 the size of a deck of cards. Eat small servings of nuts and cheeses. Fill up your plate with vegetables and fruits, and have only one roll or slice of bread. Choose a moderate dessert serving.

If you will be entertaining at home, here are some ideas for healthful foods that everyone can enjoy.

No-Chew Holiday Recipes

Pumpkin Soup

1 large onion, sliced
 1/4 cup butter
 1/2 teaspoon curry powder
 2 cups canned pumpkin
 1 1/2 teaspoons salt
 2 cups heavy cream
 2 1/2 cups chicken stock

Melt butter in skillet, add the onion and saute until soft. Sprinkle with curry powder and saute an additional few minutes. Add curried onions, pumpkin and salt to food processor or blender. Process until well mixed, then pour in heavy cream, while continuing to process. Transfer pumpkin puree to a large saucepan and heat slowly with chicken stock. Serve steaming hot. Makes 4 servings

Turkey Leftover Surprise Makes 8 servings

4 cups leftover, turkey stuffing, dressing, moistened with leftover gravy or giblet-broth - divided
 2 cups leftover cranberry sauce
 2 cups leftover turkey, sliced
 2 cups leftover pearl onions, creamed or plain
 1 cup left over mashed potatoes, in a pastry bag with a large star tip

1 cup leftover mashed sweet potatoes, in a pastry bag with a large star tip

Preheat oven to 350 Degrees

In a buttered, 4 quart, Pyrex souffle dish layer 2 cups turkey stuffing, making sure to pack it down and leaving a well in the center.

Fill the well with cranberry sauce.

Layer the turkey, onions, and remaining stuffing evenly, leaving few gaps.

Pipe rosettes of alternating mashed potatoes that cover the top.

Bake, uncovered, for approximately 1 hour or until the top is crusted and brown and the filling is warmed through.

Serve hot.

Chocolate Velvet Pudding Pie

1-3 1/2 ounce package of chocolate instant pudding and pie filling
 1 cup cold milk
 2 squares semi-sweet chocolate, melted
 1-8 ounce carton non-dairy whipped topping, thawed

Prepare pudding with 1 cup milk as directed on package, with electric mixer. Gradually blend in chocolate at low speed until smooth. Then fold in whipped topping. Spoon into dessert glasses and freeze until firm, about 4 hours. Makes 4 servings.





Our newsletter is published by the Parkinson Foundation of the Heartland to help People with Parkinson's, their relatives and their friends. It is not intended to provide personal medical advice, which should be obtained directly from a physician. Contact us at the Foundation office if you have suggestions as to how we can better serve you.

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An affiliate of the
National Parkinson Foundation

CHRISTMAS PARTY!

December 25th
2:00 p.m.

PFH Wellness Center
7800 Foster
Overland Park, KS 66204

Alone this year?
Don't want to cook or decorate?
Looking for a new holiday experience?

Join us at the
Wellness Center
for a Traditional
Christmas Day
Celebration!

Turkey with all the
Trimmings!
Deserts Galore!
Music
Good Cheer and Good
Company!
Door Prizes

Make your reservations
early, seating is limited!
Call the office at 913-341-8828
to reserve your space.



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