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A B O U T U S

The **Parkinson's Post** is published by the Northwest Parkinson's Foundation, a 501(c)(3) charitable organization.

Our mission is to establish optimal quality of life for the Northwest Parkinson's community through awareness, education, advocacy and care.

We welcome your comments on this newsletter and all our activities.



Trust me, I'm elated :- |

BY PETER DUNLAP-SHOHL

This is the February 1, 2008, post from "Off & On," cartoonist Peter Dunlap-Shohl's blog about life with Parkinson's disease.

Anyone can see *some* of the damage Parkinson's visits on those who have it. Tremor and shuffling are painfully obvious. But there is another set of problems spawned by what you *don't* see.

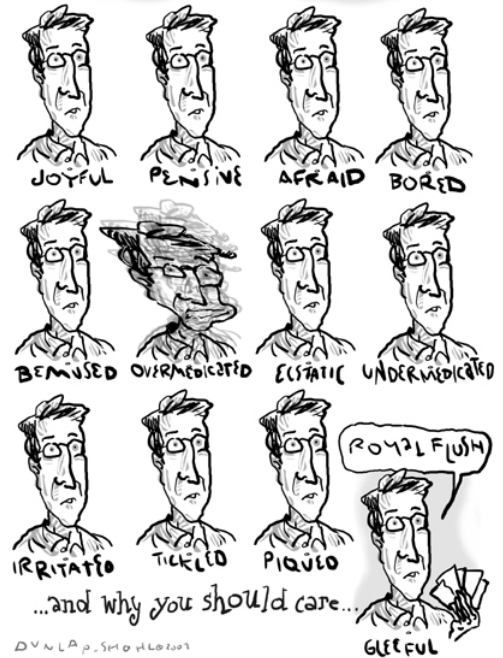
With the loss of control of facial muscles we also lose a significant chunk of our ability to communicate. Instead of expressive smiles and frowns, we present a deadpan, blank mask that unnerves others.

Much of the sense of what people say is not in the voice or words, but in the subtle visual cues and signals the face sends. We interpret speech in light of what we read in a person's expressions. Without even knowing it, people with Parkinson's can slowly lose the ability to enhance communication in this way.

Think about the problem of misinterpretation of email. The sender composes a message in which the words seem clear. The send button is pushed.

The recipient looks at the cold, expressionless type on the screen, and without the guidance of the visual and tone cues that we all use to interpret meaning, assigns meaning that isn't there. Often the missing meaning is misread and

POCKET GUIDE to DECODING THE PARKINSONIAN FACE...



DUNLAP-SHOHL © 2007

Cartoon by Peter Dunlap-Shohl

the interpretation negative.

Then consider the way we get around this problem. We insert little faces that clarify our intent, as in :-)

This is exactly what those of us with Parkinson's are *not* doing in face-to-face conversation. We are sending spoken email, without the emoticons :-(|

Instead of this :-), or this :-(|, what we send is this :- |. Nothing but :- |

To complicate things further, we are often unaware that we are not sending the proper cues. And worse, as people look for these cues and cannot find them, they

Medicare claim denied? Fight back and win

By Judith Stein, J.D.

Many seniors assume they have no choice but to pay when their Medicare claims are declined in whole or in part. In fact, denied or underpaid claims can be appealed—and more than half of these appeals are successful.

Appeals that work

When your Medicare claim is denied or approved for less than the full amount, you have 120 days to request a *redetermination* of the decision. The Medicare Redetermination Request Form (Form CMS-20027) is available on the Medicare and Medicaid website (www.cms.hhs.gov/cmsforms/downloads/cms20027.pdf) or by calling 800.633.4227.

The written claim denial you originally received includes instructions for where and how to submit this form. The claim denial includes an explanation as to why your claim was denied or why payment for your treatment wasn't covered in full. You will need to contest this explanation to win your appeal.

Ask your doctor to write a letter responding to the points raised in the denial and explaining why the health care is necessary. Include a copy of this letter with your appeals form, and keep a copy for your records.

Here are some common reasons for denial of treatment and how to fight them:

Reason for denial: The treatment, prescription, or medical service is unlikely to cause your health condition to improve. (The denial likely falls into this category if the notice you received includes words like “stable,” “chronic,” “not improving,” or “no restorative potential.”)

How to fight: The Medicare program

is required to look at your total condition and health-care needs, not just a specific diagnosis or your chance for full or partial recovery. Ask your doctor to write a letter explaining why the medical care is needed.

Example: Medicare denied home health care to a patient with Lou Gehrig's disease, an incurable degenerative condition, because the care would not help her improve. The patient successfully appealed, arguing that, while having a nurse visit her home would not improve her condition, it

If your appeal is denied, you have the right to file as many as four more. The odds of success improve the further you pursue the fight.

could slow the disease's progression and is needed to otherwise care for her various health issues.

Reason for denial: You are likely to require care for a very long time or have already received treatment for a very long time without a resolution of the problem.

How to fight: Point out that Medicare coverage is not limited to treatments that work quickly. As long as your doctor continues to order this treatment for you, Medicare should continue to cover it.

Include a letter from your doctor explaining that the treatment is having some positive effect or expressing an expectation that it will. (Medicare rules do limit how many days' coverage is available in a nursing home or a hospital but not for home care.)

Reason for denial: You do not qualify for Medicare-covered home care because you are not homebound.

How to fight: According to Medicare rules, “homebound” does not mean you're completely unable to leave your home, nor does it mean you are confined to a bed. You can be considered homebound even if you leave your home to obtain medical care or attend occasional family gatherings. You must require assistance and considerable effort to get out of the house.

Ask your care provider (who could be a family member, home-health professional, or doctor) to write a letter describing in detail how difficult it is for you to leave your home, and include this with the appeals form.

Reason for denial: The dosage level of a prescription is greater than the dosage normally prescribed, or the drug prescribed is not normally prescribed for your health problem.

How to fight: Have your doctor write a letter explaining why the unusual dosage or drug is medically necessary for you. If possible, have the doctor cite published reports of similar usage.

Example: Your doctor might explain that you are allergic to the drug normally prescribed for your health problem.

Reason for denial: Technical errors were made in the original Medicare claim. The rejection might cite a “coding error” or “incorrect Medicare recipient number.”

How to fight: Ask the health-care provider who submitted the claim to correct the problem and resubmit.

Don't give up

If your Medicare appeal is denied, you have the right to file as many as four more appeals. Your odds of success improve the further you pursue the fight. While the initial “redetermination” appeal is made to the same group that

> CONTINUED ON NEXT PAGE

Get a grip on balance with walking poles

FROM TIME TO TIME, readers contact us with good ideas to share with the Parkinson's community. One very good idea came recently from Canadian reader Bill Trewin, 55. Trewin, who lives in Moncton, New Brunswick, is reaping the benefits of *Nordic walking*.

Also known as ski walking and pole walking, Nordic walking is a form of exercise that involves walking with special poles that can be purchased at sporting-goods stores. As Trewin points out, the poles aid in balance, something a good number of people with Parkinson's struggle with.

In fact, Nordic walking is so compelling that researchers at Arizona State University are studying its affects on people with Parkinson's disease. (Visit our website at www.nwfp.org/News.aspx?Item=2607 for a story

about this study.) The research stems from prior studies into the neuroprotective effects of exercise.

Here's Trewin's first-person account of Parkinson's and Nordic walking:

In my case Parkinson's wasn't all of a sudden—it was gradual. The first thing I noticed was that my right foot began to scuff. Then I noticed my briefcase would strike my right leg as I walked. I also began to notice small tremors in my right hand.

My doctor felt my symptoms were a result of the stress I was under.

Then, when the tremors got more pronounced, any stress got me shaking. My thought process was, at best, a fog most of the time. Rigidity became more noticeable—my right arm didn't

swing at all when I walked.

At 49, and with the help of three neurologists, I got my diagnosis.

About three and a half years ago a couple of my friends introduced me to Nordic walking. Since then I have done a full marathon (just over 26 miles) and eight half marathons.

The Nordic walking poles help with balance issues and stimulate my right side. I have also found that using an MP3 player with music at a beat that is comfortable for me can get my right leg and arm doing very positive things.

As a former runner, I'm glad to be out there again.

The T-shirt I wear at walking events reads: "I have Parkinson's . . . it doesn't have me."

For me, exercise is every bit as important as medication.

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initially denied your claim, later appeals are made to increasingly independent arbiters.

♦ *Appeal #2:* You have 180 days from the date your redetermination request is denied to request that a qualified independent contractor (QIC) make a *reconsideration determination*. You will have to complete the Medicare Reconsideration Request Form (Form CMS-20033, available at www.cms.hhs.gov/cmsforms/downloads.cms20033.pdf).

If the redetermination denial includes any reasons for denial not mentioned earlier, ask your doctor to write a new letter. Otherwise, attach a copy of your doctor's earlier letter.

♦ *Appeal #3:* If your second appeal is denied as well and the amount in dispute is at least \$120 (\$200 for a hospital inpatient claim), then you have

60 days to file a third appeal, this time with an administrative law judge (ALJ) of the U.S. Department of Health and Human Services. Filing instructions are included with the denial. ALJ appeals are presented to the judge via telephone (or videoconference if you have the necessary technology). At the beginning of the hearing confirm that the judge has a copy of any letter of support written by your doctors. Then explain your situation and why you require the care in dispute.

Helpful: Judges are supposed to rule based on the evidence and the law, but they are human. It never hurts to remind the judge that you are living on a fixed income and that you would face major financial problems or even health problems if Medicare fails to pay this bill and/or approve the treatment.

♦ *Appeal #4:* If the judge turns down your third appeal, you have 60

days to request that the Medicare Appeals Council (MAC) review the decision. The ALJ denial will include instructions on how to do this.

♦ *Appeal #5:* If the MAC turns down your appeal, you have 60 days to determine if you wish to hire an attorney and file a judicial review for Federal District Court. The amount in dispute must be greater than \$1,180 (\$2,000 for a hospital inpatient claim) to qualify. (This amount may change each year.) For more information, contact the Department of Health and Human Services at 877.696.6775 or www.hhs.gov/omha.

Judith Stein, J.D., is founder and executive director of the Center for Medicare Advocacy Inc., a nonprofit advocacy organization that provides assistance with the Medicare system (www.medicareadvocacy.org). This article is reprinted with permission from the author.

Treating sniffles safely means knowing what's in cold medications

Q: What cold medicines can I safely take with Parkinson's drugs?

A: This is the time of year when you may find yourself browsing the medicine aisle in your local pharmacy searching for a preparation to treat cough and nasal decongestion associated with the common cold. Many cold preparations contain the warning that they should not be used if you are taking Parkinson's medicine.



ASK THE EXPERT features questions from readers and responses from Monique Giroux, M.D., medical director of the Booth Gardner Parkinson's Care Center in Kirkland, WA. Got a question? Email it to questions@nwpf.org, mail it to 400 Mercer Street, Suite 401 | Seattle, WA 98109-4641, or call us toll-free at 877.980.7500.

There are general precautions to help you safely treat your cold without medicine interactions.

First, it is important to know what is included in cold preparations before selecting and buying a product for your cold. Because of potential side effects or medicine interactions, it's a good idea to check with your doctor or pharmacist before taking a cold medicine.

Over-the-counter cold preparations often contain a mixture of ingredients for specific needs. There are non-drowsy formulas, formulas to help you sleep, long-acting formulas, and formulas for coughs and the flu. The most common ingredients are antihistamines, decongestants, cough suppressants, and fever or pain relievers.

An antihistamine or allergy medicine reduces itching, inflammation, and allergy symptoms such as runny nose and

watery eyes. A common antihistamine is *diphenhydramine* (found in Benadryl). Common side effects of some antihistamines, especially diphenhydramine, are sedation, cognitive changes, constipation, and dizziness.

The side effects associated with diphenhydramine are confusion and excessive daytime sleepiness, both of which worsen imbalance, affect driving, and increase falls.

Antihistamines can increase the sedation affect of drugs such as *benzodiazepines*—used for anxiety or as muscle relaxants—and increase the effect of blood-pressure drugs.

Long-acting formulas offer longer cold relief, but a night-time dose taken in the daytime is more apt to cause daytime somnolence.

Newer antihistamines such as *loratadine* (found in Claritin) cause less sedation and therefore may be better tolerated. Be sure not to take extra doses of antihistamines as some sleeping preparations such as Tylenol PM also contain diphenhydramine (the ingredient in Benadryl).

A decongestant constricts or narrows blood vessels in the nasal lining, reducing inflammation and swelling to help open up your nasal passages to aid breathing. Common decongestants include *phenylephrine* and *pseudoephedrine*. Side effects include dizziness, heart palpitations, and agitation.

Decongestants can increase the effect of stimulants such as caffeine, increasing anxiety, insomnia, agitation, and tremor. Decongestants must not be used with Parkinson's medicines that are MAO-B inhibitors, such as *selegiline* (found in Eldepryl and Zelapar) or *rasagiline* (found in Azilect).

You must stop your MAO-B inhibitor two weeks before taking a decongestant. This combination of medicines can cause heart palpitations and a serious elevation in blood pressure.

A common over-the-counter cough suppressant is *dextromethorphan*. This medicine should not be taken with MAO-B inhibitors as the combination can cause serotonin syndrome with agitation, sweating, tremor, muscle jerks, diarrhea, fever, and heart palpitations.

Common fever and pain relievers used in cold preparations to relieve achy muscles, headache, and fever include *acetaminophen* (found in Tylenol) and *ibuprofen* (found in Motrin). These medicines do not interact with Parkinson's medicines, but be careful not to take more than your doctor recommends.

Because there are so many brand names to choose from, and since the ingredients in any one pill can be difficult to determine, be sure to follow the practical tips on the next page when you are considering cold medications.

Take care before you take cold medications

- ♦ Ask your doctor to recommend a cold medicine *before* you get a cold, rather than wait until you need one.
- ♦ Always read the label to know what you are taking.
- ♦ Don't take it if you don't need it. For instance, do not take a cold medicine with a cough suppressant if you do not have a cough.
- ♦ Buy your cold medicines (and all over-the-counter pills) at the same pharmacy where you fill your prescriptions. Pay for over-the-counter medicines in the pharmacy department rather than at the general check-out counter. This way your pharmacist can check to see if there is an interaction between what you are purchasing and your prescription medicines. If you get your prescriptions by mail order, be sure to have a complete list of all your medicines on hand to show the pharmacist.
- ♦ Be sure to include *all* your medicines—including over-the-counter pills and supplements—on your list as these, too, can interact with your Parkinson's drugs. For instance, some herbal preparations, energy or weight-loss pills, and sleep aids contain stimulants similar to those in decongestants or antihistamines.

Levodopa and protein: The debate continues

By **Lindy Wood**

The first time you picked up your Sinemet from the pharmacy, you were probably told to take it on an empty stomach. But maybe you found that the medication upset your stomach and you were then advised to take it *with* food.



So when it comes to carbidopa/levodopa, the drug combination in Sinemet, the question is *to eat or not to eat?* The answer: *It depends.*

Why is food an issue with carbidopa/levodopa? When you take this medication, it goes into your stomach, where it is absorbed into the blood stream and then into the brain. The reason you are told to take it on an empty stomach is because the amino acids in foods, particularly those high in protein, can compete with the levodopa to be absorbed.

When you're absorbing less levodopa, you may not be receiving the full effects of your medication.

Many people can take levodopa with a meal and not notice any difference over taking it on an empty stomach. Others notice considerably more "off" time when they take their carbidopa/levodopa with a high-protein meal, such as steak or chicken.

If this has happened to you, you are likely more sensitive to the effects

of protein on levodopa's absorption, and you should try to avoid taking levodopa with a high-protein meal.

It's important to know that protein sensitivity with levodopa can increase as Parkinson's advances.

A good rule of thumb with carbidopa/levodopa is to take it on an empty stomach, about 30 minutes before eating or an hour or two after. This is especially true for people who are protein sensitive.

But if you find it upsets your stomach, go ahead and take it with some food. Some people take their Sinemet with food but try to avoid high-protein choices, or they eat small meals throughout the day to spread out

When you're absorbing less levodopa, you may not be receiving the full effects of your medication.

the protein they're taking in. Crackers, bread, and granola bars are good low-protein options to take levodopa with.

The most important thing is that you are taking the carbidopa/levodopa as prescribed and receiving its benefit.

If you have concerns about the effects of food, or if your medication is making you nauseated, talk to your health-care provider or pharmacist, who may be able to offer tips or adjust your dosage.

Lindy Wood, pictured here, is a doctor of pharmacy candidate at Washington State University in Spokane, WA, where she is in her fourth year of study.

Low blood pressure study seeks subjects

DO YOU OR SOMEONE YOU KNOW have trouble with orthostatic hypotension (low blood pressure)?

The Booth Gardner Parkinson's Care Center at Evergreen Hospital in Kirkland, WA, is seeking participants for an international study of a new experimental treatment for orthostatic hypotension.

You may have orthostatic hypotension if you have dizziness associated with a drop in blood pressure when standing.

You may qualify to take part in the study if you are 18 or older and have been diagnosed with orthostatic hypotension—dizziness when standing associated with a fall in blood pressure measured after standing for three minutes—that is secondary to a neurologic cause or condition.

Those with diabetes, atrial fibrillation, or significant cardiac arrhythmia may *not* participate in the study.

Study participants will receive:

- ♦ an evaluation of their orthostatic hypotension;
- ♦ study-related medicine and study-related medical care; and
- ♦ the possibility of helping future orthostatic hypotension patients.

Participation in this study does not affect the treatment of other medical conditions, and participation in any research study is confidential and voluntary.

For more information, call the research coordinator at 425.899.3126 or 425.899.3115.

Evidence backs benefits of exercise in Parkinson's

By Kevin Lockette, PT

The key to an effective exercise program with Parkinson's disease is to focus on posture and purposeful movement. The postural muscles are vital to maintaining the range of motion you need to carry out the activities of daily living.

These muscles are also critical for balance in that they help you keep your center of gravity over your base of support (your feet), which prevents you from falling.

The main postural muscles are the scapular muscles, the muscles of the upper back, the back and hip extensors, and the quadriceps.

The stronger your postural muscles are, the better equipped you will be to battle *forward posturing*. This is the tendency in Parkinson's to lean forward in a stooped posture, which can trigger *freezing* (the sudden inability to take a step) and *festination* (a shuffling gait).

We all know exercise is good for us—for cardiovascular conditioning, for building muscle to support aging bone, and for staying flexible. But exercise has special benefits for people with Parkinson's, and not just for the body but for the brain.

One University of Southern California study looked at treadmill exercise in mice with reduced dopamine-producing capacity, comparing outcomes against a group of normal mice. (In Parkinson's disease, the brain's dopamine-producing neurons are diminished.) In the mice with neuron loss, exercise showed a positive effect on dopamine levels.

An Italian research group evaluated the capacity of a rehabilitation exercise program to improve mobility in people with Parkinson's. The researchers found statistically significant improvements in the subjects' motor performance after they had gone through the program.

And researchers at Washington University recently noted significant improvements to functional mobility in groups of study subjects who took tango lessons and exercise classes. Those who took tango classes showed the greatest improvement in balance.

More research is underway to better understand the effects of exercise on Parkinson's disease.

The bottom line is that exercise is one thing you can do to combat the physical symptoms of Parkinson's. There are many modes of exercise that are appropriate for people with Parkinson's, including tai chi, Pilates, dance, and resistive training.

A exercise program designed specifically for Parkinson's can help improve posture, reduce the affects of fatigue, improve mobility, and decrease the incidence of freezing and falls. Ask your health-care provider or physical therapist to advise you on exercises to help with your Parkinson's.

Kevin Lockette is a Hawaii-based physical therapist with 20 years' experience working with people with neurological issues. He is the author of a new book and DVD on Parkinson's called Move It—An Exercise and Movement Guide for People with Parkinson's Disease. For details, visit www.parkinsonsmoveit.com.



TRIBUTE GIFTS

Gifts to the Northwest Parkinson's Foundation support educational programs including our website, email updates, caregiver booklet, newsletter, patient-education programs, and conference. Gifts also fuel our outreach and advocacy efforts on behalf of patients and families. We are privileged so many in the Northwest Parkinson's Foundation family support our mission by giving generously throughout the year in honor or memory of special

friends and loved ones. We list tribute contributors in each issue of the *Parkinson's Post*. (All donors are recognized in our annual *Report to Contributors*.) Listed here are those who made tribute gifts from **January 1 to February 10, 2009**.

Something new: family funds

With a minimum donation of \$2,500, family members and friends can create a family fund in honor of a loved one. Gifts we receive through the creation of family funds will support general operations and be listed permanently in our newsletter and on our website. Contact Keri Kellerman at 877.980.7500 or keri@nwpf.org to learn more.

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Pedaling, striding, climbing toward hope

Team Parkinson's comprises people with Parkinson's and their family, friends, neighbors, coworkers, and caregivers. Team members participate in biking, running, jogging, walking, mountain climbing, hiking, swimming—and just about any other

challenging endeavor or activity that can be used to get in shape and raise funds and awareness for Parkinson's.

Team members collect donations that support Northwest Parkinson's Foundation programs and services.

A lot of Team Parkinson's members favor biking events (the Group Health Seattle-to-Portland Bicycle Classic is our most popular). Others favor running events like the Amica

Insurance Seattle Marathon, which includes a full marathon, half marathon, 5K run, and kids run.

You can turn any event or activity into your personal Team Parkinson's effort by registering for the team at www.nwpf.org/GettingStarted.aspx. Here you can create a personal web page to share with family and friends. Go online today or call us toll-free at 877.980.7500 to learn more.



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get frustrated, confused, and sometimes angry.

Once, while taking care of some support-group business at a bank with my friend Lory, I sensed rising irritation in our banker.

I was at a loss as to the cause until I realized she was interpreting our Parkinsonian lack of expression as anger. I stopped the rapidly deteriorating meeting and explained our featureless expressions.

The change was immediate and dramatic. She went from grim to jovial in seconds flat.

And Lory and I, having solved the mysterious problem, were elated :-|

Peter Dunlap-Shobl, 50, blogs from Anchorage, AK, where he lives with his wife and son, works as a cartoonist, and leads the Anchorage Parkinson's Disease Support Group. You can enjoy more of his posts at offandonakpdrag.blogspot.com.