



LATEST TIPS FOR PERSONS WITH PARKINSONS

3rd edition

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This booklet expresses only the personal opinions of the authors and is not intended to offer medical advice. Always consult your personal physician for medical advice.

This booklet is distributed by National Parkinson Foundation Central & Southeast Ohio Chapter, a non-profit organization serving those afflicted with Parkinson's Disease, their partners and families. The society publishes a monthly newsletter with information for both patients and caregivers as well as establishing local support groups. Completing the form inside the back cover will add your name to the list of those of us fighting Parkinson's disease. If you reside in central or southeast Ohio, we can put you in contact with a nearby support group.

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This collection of mostly unpublished tips is merely a sharing of ideas. No responsibility is taken by the author or publisher as there is no control over the circumstances of the user(s). Always seek your Doctor's advice.

For convenience sake an attempt was made to group these items by whatever category they seemed to fit best, and may not be listed in the same order that you would place them.

Make life a little easier by using common everyday items found in and around the home. Some of these ideas are unique but they may get the job done and save you a dollar or two.

Support groups

The most valuable of tools available for the Parkinson's Victim. Whether patient or caregiver, the members of the support group have experienced in real life the symptoms that you are and will be encountering and have to live with.

Medical treatment

Find a neurologist whose practice includes Parkinsons' Patients. Parkinsons' is a disease that varies with the individual and its symptoms are seldom the same for each person. You will need all of the help available and it should be first hand knowledge. See Your Doctor in all matters regarding your treatment.

Pills and medication

You can avoid the problem of getting pills stuck in your throat by drinking half a glass of water before taking your pills and taking the other half after taking the pills. This will help in keeping the throat slippery and expedite the pills journey to the stomach. Tilt your head forward, not back, when swallowing a pill.

There are empty gelatin capsules available for purchase at health food stores and pills may be placed in one to assist with the problem of pills getting stuck in the back of the throat.

Timing

If the first medication of the day varies as to timing, write the actual time on a post-it note and put that on your pill case to help keep on track of your daily medication schedule.

Missed (late) pills

If you missed taking your pills on time (and you will) change the time interval and maintain it for the rest of the day. If you were on a 2 hour schedule and at 4 p.m. you discover that you missed your last pills, 3p.m., take the 3 p.m. pills immediately (at 4 p.m.) and then go to 6 p.m. for your next scheduled pills. Maintain the 2 hour frequency for the balance of the day and go back to your regular schedule the next day. **DO NOT ATTEMPT TO DOUBLE UP OR CATCH UP AS YOU WILL BE RUNNING INTO THE UP AND DOWN SYNDROME.**

Critical timing

Parkinson medicines do not work well with protein which slows down the absorption rate. Allow at the very least 30 minutes either side of a meal when taking your pills. Allow extra time after a heavy meal.

Sinemet

If this medication upsets your stomach, try taking it with water and crackers.

Handling medications

A great way to handle medications is to sort out all of a week's or a month's supply. Get 30 small plastic bathroom cups (3-4 oz) and in each cup place the number of pills of each medication that you use daily. Then each day you can sort out one cup for that day's use. If you lay out a monthly quantity, you will have minimized the work necessary to control your pill supply and assist in monitoring refills and requests for new prescriptions.

Difficulty turning

In bed

Sew a square of satin onto the seat of a pair of pajamas and sew another square of satin to the bottom sheet; this expedites moving in bed. Sleeping in acrylic, silk or satin bedclothes will cause less friction when moving in bed. Satin sheets are available. Electric beds allow you to get into a sitting position before getting out of bed. If medically necessary, it may be tax deductible or reimbursable by insurance; consult with your advisor. Obtain a nylon rope about $\frac{3}{4}$ " in diameter and about 12 feet long. Tie a single knot in the rope about every 12" or so, to use for handles. Attach one end to the corner of the bed frame and run the rope on your side of the bed so that it will be there if you need it to move in the bed or to pull yourself up. This is handy to help in moving across the bed or for those who cannot roll over.

Too much bed movement

Take a bath size towel and fold it over once or twice and then roll the towel into a log about 4 inches round. Tape the towel in 3 or 4 places so you end up with a rolled up towel. Tuck the log along side of your body and it will help minimize tossing and turning.

In a car

A plastic bag or a piece of silky material placed on the car seat is helpful for getting into or out of a car.

Getting out of a chair

Try rocking back and forth 3-4 times and then try to get up.

Foot and leg cramps

Try using NuSalt (potassium chloride) in place of regular salt (sodium chloride).

Dyskenesia

This may be minimized by holding a plate or glass made of Arcorac or other similarly tinted blue glass and looking through it for 5-10 minutes.

Dry mouth

Peel and section a couple of oranges and put the pieces in a zip lock bag and carry it with you. A slice or two will alleviate dry mouth. Also try Lemon Ice, Popsicles or sugarless Hard Candy. Suck on ice or ice chips. Biotene mouth wash, gum and gel are available for dry mouth.

Clothing

Elastic shoelaces allow you to tie your shoes once and then treat them as slip on loafers afterwards. If buttons are a problem try Velcro fasteners. Some shirts are made with snaps instead of buttons.

Robe/bed cover

Cut a sweat shirt in half up the back to the collar (Do not cut through). Leave the sleeves on and leave about 2 inches on the backside collar so you have some support on the neck. Put the garment on backwards with your arms going into the sleeves (like a hospital gown). This is a great way to read in bed while lying on your back and still keep warm. Plaid or print clothing doesn't show spots as much as solid colors.

Dressing

Use pants with drawstring waist rather than buttons and zippers.

Showering and bathing

"Soap on a Rope" prevents dropping slippery soap in the tub or shower.

Shower chair

This will provide stability. Some are height adjustable and some have built in trays for storage of items. Electric toothbrushes are recommended for ease of use. Waterpicks can assist in cleaning your gums when flossing becomes difficult. Stick your toothbrush in the little hole at the back of the sink while you put on the toothpaste. Grab handles by the tub, toilet and shower are essential.

Address labels

Attach a luggage tag or return-address label to a walker or wheelchair Identification. Also use these labels when filling out forms.

Eating

An electric warming tray keeps food hot for those who take longer to eat; styrofoam or insulated cups also help. Wooden utensils are ok for display but not for cooking. Bacteria love to get caught up in them. Use items that are non-porous like stainless steel. Use plates that have rims on them to assist in managing food. Also available for rims to place around dishes; these are found in medical supply stores and catalogs. Drinking Straws. These help individuals who have problems holding a glass without spilling the liquid.

Fold dollar bills in half in your wallet for easier access.

If blankets feel too heavy on your legs use a blanket lift to keep them off your feet.

There are both male and female handheld urinals.

Voice

Yell or shout or sing loudly while in the shower or in the car to keep your voice strong. Singing is good exercise for your voice. Speech and voice exercises should be done and classes may be found locally or exercises may be researched through your doctor or library.

Posture

Look in the mirror when brushing your teeth and straighten your back.

Walking

Practice taking large steps and remind yourself by shouting "large steps". Space objects across the floor and try to walk over them. Place colored tape on the floor at intervals and aim for them when walking. You can vary the colors also. Install "grab handles" on walls adjacent to door knobs so you have a steady grip while you pull on a moving doorknob. Arrange furniture so as few changes in direction are needed as possible. The straighter the walk from point A to point B the better.

Shuffling

Try leather soled shoes rather than rubber soles. Rubber soles can catch and cause a loss of balance.

Freezing

Have a caregiver extend a shoe in front of the PWP so that the PWP can step over it. Use a walker or cane with a laser light beam.

"Touch on" lamp can be helpful.

Using chairs with rollers often helps getting around the house.

A twin bed allows exit on either side.

Handwriting

Try using a soft, felt tip pen; it will not need as much pressure as a ballpoint. Use a voice recorder when you need to make a note. Speakerphones assist with a shaking handset and also assist with a hearing problem. Keep a note pad and pen on your night stand. Our experience is that you may not be able to read what you have written but give it a try and you may recall your thoughts.

Water consumption

To drink water to remain hydrated, fill a liter bottle in the morning and use that for drinking throughout the day. You will be able to easily monitor your consumption.

Travel

Ask the airline for wheelchair service at all points. Consider booking airline seats where the patient and partner have opposing aisle seats for ease of movement (bathroom, exiting). Ask for a handicapped accessible room at hotels.

Audio books

Check your library for a catalog; a wide variety is available.

Medicine

Always carry at least one day's supply of medicine with you for emergencies.

Parking

Obtain a state handicapped parking permit. Your doctor will need to complete a form for this.

Difficulty opening containers

Try using zip lock bags. Puddings, scrambled eggs, etc., can be prepared in zip lock bags.

Seborrhea

Regular dandruff shampoo can be used on the head and forehead for assistance with patchy, scaly, skin.

Exercise

Regular exercise is vital to maintaining physical abilities and flexibility. There are Parkinson specific exercise DVD's available. Join an exercise group. Try swimming, walking, Tai Chi, aerobics. Always consult your physician before starting new exercise routines to determine if there are limitations involved.

Legal documents

Review and complete legal documents; such as a Will, Durable Powers of Attorney, Health Care Documents. Decide what your desires are for final disposition. This is the hardest decision to make and it's not something that should be avoided. Remember to discuss your decisions with your family members.

Catalogs of handicapped adapted items are available from Sears and J C Pennys. Also check the internet. Check local medical supply companies.

Handi-wipes

Excellent to have on the nightstand and in the car; anyplace where you might need a refresher when you can't get to a sink. A similar idea for those who suffer from excessive dry skin is to take a washcloth and get it wet; wring it out and place it in a zip lock baggie. Keep this on your nightstand and use it to relieve the feeling of "tight, dry skin". Also, this can work with a damp washcloth that you place some hand/skin cream on and place in a baggie; this also relieves the "tight, dry skin". If you keep the zip lock baggie under your blanket it will be warm when used.

Car information

Information that should be in every car: Package up a days' supply of pills and place it in your cars' glove compartment. Rotate periodically for freshness. Keep a list of pharmacy and doctor phone numbers. Keep an up to date list of all medications, their strength and dosage information. Go for a dry run to the hospital. Park and find your way to the emergency room. Do this several times and get it down pat.

Back problems

It seems that most everyone has some back problems and a lot of this may be the result of uncontrolled body movements grinding away at the back. One simple possible help is the use of shoe liners or seat cushions.

Pill case

Use a pill case to manage your medications. Taking multiple pills on a time restricted basis cannot be accomplished if you are trying to sort out pills when you need them. Compartmented pill cases come in a variety of sizes and prices; some are available with timers.

Scored pills

These can ease breaking pills in half for those trying to peak out their meds. These have to be explored with the pharmacist and /or your doctor on an item by item basis. Purchase a pill cutter if your doctor agrees with using half pills.

Timing

If you start your medications each day while still in bed and have some difficulty doing so, try this idea. Take 3 little plastic cups and in the 1st cup put nothing. In the 2nd cup, put your 1st morning meds. In the 3rd cup place your 2nd set of scheduled meds. Now nest the empty 1st cup into the 2nd cup and nest these two cups into the 3rd cup. Place the package on your night stand. When it's time to start your daily routine, the empty 1st cup will prevent you from dropping any pills while handling the cups. Take the empty 1st pill cup off and the next cup has your first pills. Leave the empty cup on top and again, you will not drop your next medications while reaching for it later. I have actually dropped my 3 pack on the floor and have picked it up without getting out of bed and without losing my pills.

Weight problem and Nutrition

Ensure (several companies make equivalent products) will help with calories and vitamins.

Empty RX bottles

Save an empty bottle of each medication. If you travel, you have the actual bottle to identify the pill.

Unusual pill problem.

We had a request from a member who was having a problem with dropping pills and not being able to find them, so we investigated. While we were unable to solve his problem completely, we did help somewhat by relocating his chair from the living room to the kitchen. This was a big help as before he moved he was on carpet and in the kitchen he was on tile and he had a better chance of finding the pills as he could hear them when they hit the floor. Best advice is to sit at a table.

Sinemet Delays

If your Sinemet is slow to kick in in the morning, you might want to try using a Sinemet CR (SR or ER) about an hour or so ahead of your first meds. The slower release CR lessens the reactions to the chemicals. and makes mornings a little more pleasant. See your Doctor. It may be worth a try.

Crackers

When a pill becomes lodged in your throat, chew a cracker then wash it down with a glass of water. Saltines are available in a two piece pack in the bulk foods department of some grocery stores and can be kept in the car for difficulty while traveling.

If you have low blood pressure and get dizzy when you sit up suddenly take a little salt to relive dizziness. Discuss this with your Doctor.

Generics

Ask your Doctor to write your scripts for generic meds. Generally, they will provide the same results as the more expensive brand name medication.

Memory aids

Leave notes to help remember things. Leave directions on how to use the microwave. Keep a list of important instructions at the same place in the house. Keep a list of all medications (prescription and vitamins) and doctor's names and phone numbers in several places; in each car and also in the kitchen handy to grab in an emergency.

Bed mattress

A solid piece of foam 6 "thick in either firm or soft will serve as a terrific mattress.

Use a walker or cane with a laser light beam.

Dried and calloused feet

Get two plastic grocery bags and place a substantial amount of your favorite skin lotion in the bottom of each bag, Put your foot into the bag and knead the foot until the foot is covered with the lotion then take the plastic bag and wrap it around your ankle and secure the plastic bag then place the whole foot into a sock and put on your shoe. Do the other foot. Leave it on for several hours or overnight. This also assists when clipping toenails.

You can use any liquid to wash down your pills with the exception of Grapefruit. This fruit contains an acid that interferes with the absorption of Sinemet.

Kitchen waste management

Take a cereal box, cut in half to a reasonable size and place a plastic grocery bag inside. Place on the kitchen counter near the sink. This is very handy for small scraps, trash, coffee grounds and other daytime trash. It will cut down the number of times you have to open the cupboard door to stoop over with some trash. After doing the dishes throw the plastic bag away and put a new bag in the box. When you get tired of the scenery buy another box of cereal.

Support groups

Yes I know we already mentioned support groups but it's so important that we thought we would address it again. Join one now. At least attend a meeting. In a support group you will find others who have been diagnosed longer than you and can provide answers or direct you to appropriate resources. Support groups are also a valuable resource for caregivers and there are also support groups specifically for caregivers. If there isn't one nearby, start one. We'll help you.

I want to subscribe to your monthly newsletter

I want to donate to your efforts

Name **(Please Print)**

Address

City _____

State _____ Zip _____

Phone Number _____

Email _____

Do you belong to a Parkinson's Support Group? Yes No

If not, would you be interested in joining? Patient Support Group

Caregivers Support Group

Newsletter will be read by:

Patient (Name) _____

Caregiver (Name) _____

Parkinson Patient's Family

As an MD

Nursing Staff

Other

The National Parkinson Foundation Central & Southeast Ohio Chapter does not charge annual dues, relying instead on donations. Our services are freely given to any patient or caregiver requesting help without any consideration of income. Many patients are elderly and on fixed incomes with high prescription expenses and cannot afford to give. We need your help.

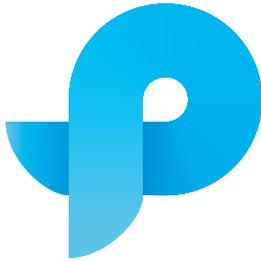
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