



# THE AMERICAN PARKINSON DISEASE ASSOCIATION, INC.

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## EDUCATIONAL SUPPLEMENT #9

# Helping Your Partner What Not To Do!

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**M**any people when faced with a loved one being diagnosed with Parkinson's disease (PD), tend to overreact as they cope with his affliction and the possibility of changing roles. Below we have outlined some of the things that you should not be doing as you and the person with PD adjust your lives and your daily routine to this intruder.

### **DO NOT RUSH**

**STRESS** - Putting the person under stress will make the PD symptoms worse and actually slow the patient down. Use time management techniques instead.

**Prioritize tasks** - Plan ahead for parking, reservations, etc...

**Plan to be early** - Assist person with PD, only if necessary.

**BRADYKINESIA/AKINESIA** (Slowness of movement or difficulty initiating a movement) - You must have patience or a plan to deal with these impairments or you will "go crazy."

*Have something you can do while waiting, such as listening to music, reading, knitting, or answering the mail so you won't feel like you are wasting time. Learn relaxation techniques to help supplement your "patience of a saint."*

**MOVEMENTS** - Cue, touch or support.

*Sometimes talking to a person through a movement, touching them on the back, putting your hand out or giving minimal physical support can help the person with PD do chair, car and toilet transfers or walk better.*

## **DO NOT BANG YOUR HEAD AGAINST THE WALL**

### **PHYSICAL ACTIVITIES**

*Plan for major activities during "on" times, if possible. Have contingency plans for "off" times.*

**MENTAL ACTIVITIES** - If the patient is one of the minority with PD who have mental impairment.

*It may be difficult to get the person to learn new information, to remember things that happened recently or to use good judgement. Trying to get him/her to think as they once did may cause more stress for you and the person with PD.*

**REMINDING** - A person with PD may know all the right things to do and may be a motivated participant in therapy and support groups and still not do what he/she should.

*Prioritize those things you remind the person to do so that you are not perceived as "nagging." Encourage exercise, the use of adaptive aides or assistive devices and the avoidance of behaviors that can cause falls. Correct walking (lifting feet, using a cadence, marching) and speak loudly.*

**REORIENTING DURING PERIODS OF MEDICATION-INDUCED PSYCHOSIS** -

When a person is hallucinating or paranoid, it may be difficult to reason with them as you would when he/she is not. If a person has vivid dreams or "parasomnias":

*Have your doctor treat these side effects which may occur with certain medications. Remind the patient that although what he/she sees may seem real, it may only be a hallucination caused by medication. Try to make the person feel safe and wait it out; DON'T argue!*

## **DO NOT ASSUME**

### **INTERPRETING A PERSON'S FEELINGS**

Just because you have lived with a person for 50 years, do not assume that you know what this person is feeling. Sometimes PD can make a person's facial expression become blank with eyes that stare in the distance. The smiles, interest, love and frustration that you could once see may not be reflected in that face anymore. Because the ability to produce speech, to concentrate on conversations and to find the right word may become more difficult in PD, do not assume that the person has nothing to say. Instead, try:

- *Finding a quiet place to talk*
- *Having a one-to-one conversation*
- *Allowing more time for the person to concentrate and answer.*

**PERSONALITY CHANGES** - Sometimes people have subtle or more obvious personality changes that may be due to PD. Sometimes those people with PD will

not want to let their spouses out of their sight and may want to accompany them everywhere. Find out why:

- *Is the person afraid of falling or being alone?*
- *Is the person jealous or afraid that the spouse may be having an affair?*

A gregarious person may become withdrawn and not want to be involved socially anymore.

*If this is due to depression, it is very treatable. It may be due to embarrassment because of tremors, difficulty moving, drooling or eating. Ask your doctor to treat these symptoms or refer to physical therapy, occupational therapy, speech therapy or counseling. If the symptoms persist, comfort and acceptance can be found in a support group and eventually with friends when the discomfort is addressed.*

*Acknowledge the "elephant in the room". Sometimes bringing attention yourself to tremor and dyskinesia can dispel anxiety by getting any questions out of the way and by helping everyone to focus on the activity at hand without distraction.*

**ANGER OR UNPLEASANTNESS** - One of the stages of grieving over losses caused by PD is anger.

*You might accept this for a while but if the anger persists, get help. Family members should not allow the patient with PD to get away with unacceptable behavior unless they are confused or having medication-induced psychotic problems such as; paranoia, hallucinations or striking out during vivid dreams. These behaviors need to be brought to the attention of the doctor and treated.*

## **DO NOT INSIST ON "NORMALCY"**

### **LIFESTYLE**

Your daily activities may need to change.

*Some chores or activities, such as dusting, vacuuming, cleaning, yard work, house maintenance, caring for grandchildren and food preparation may have to be eliminated, reduced or delegated. Clothing styles may need to be adapted to make dressing, undressing, toileting and walking easier.*

Accessories such as ties, pantyhose, belts, zippers, coats, shoes and underwear may cause difficulties when dressing. Adapt when possible with Velcro. Choose loose fitting clothing with stretch waists and simple closures.

**SIMPLE IS BETTER.** Save the "dress-up" clothes for special occasions and help to tie ties, put on jewelry, scarfs, etc. Fanny packs instead of wallets or handbags may be easier and safer. Permanent-press

clothes will save you ironing and trips to the cleaners.

*Grooming styles may need to be modified.*

For men, growing a beard is one way to avoid problems while shaving. For women, shorter hair, permanents or easy hair styles may allow them to spend less time preparing for the day. Hairdressers can dye eyebrows, eyelashes and even "tattoo" an eyeliner, if make-up is a big problem.

*The house may have to be rearranged and decorating concessions made. Avoid scatter-rugs, thick pile carpeting and door jambs which can cause walking problems and falls. Even beautiful end tables, plants, vases, etc.,*

*may constitute obstacles that cause difficulty in walking, freezing and falling. Use tub seats, hand held showers, raised toilet seats, bed hoops and bed rails. They may not fit into your decor - but they may make daily activities easier. Sleep in separate beds if vivid dreams, bed mobility problems or frequent awakenings disturb the partner's sleep. (Don't forget, you can always climb back in bed to cuddle together.) You may have to change roles. The other spouse may have to do all of the driving, pay bills, work, plan social activities, make decisions and take the lead in sexual activity if PD becomes more advanced.*

Last of all **Do Not Expect To Be Perfect!**

Doing your best with a loving heart and good communication is all one can ask for.

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The information contained in this supplement is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's own physician.



American Parkinson Disease Association

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