

Coping With Dementia: Advice for Caregivers

Parkinson's disease is known primarily as a disorder that impairs movement. For some people with Parkinson's (PWP), however, there are other disabling symptoms of Parkinson's. Coping with dementia, including difficulties with memory and slowed thinking or communication, is a challenge to PWP and caregivers alike. Recognizing the signs and designing appropriate coping strategies can enhance a PWP's level of function as well as self-esteem.

So, while the subject of this article will certainly not pertain to all of our readers, we hope it can be of benefit to those who may be faced now or later with these symptoms, as well as to those coping with caring for them.

At the outset it is important to understand that memory lapses, confusion or slowed communication can be due to a variety of problems such as stress, medications or depression. Therefore, patients who experience such problems should discuss them with their doctors before jumping to conclusions about their thinking difficulties.

When discussing dementia, we often think about Alzheimer's disease, in which people experience memory difficulties, but also may have problems such as making mistakes with words or trouble planning and performing daily tasks. In fact, dementia in PWP may be due to coexisting Alzheimer's disease. However, dementia in Parkinson's can take a somewhat different form and so it often presents a quite different set of challenges. In addition to forgetfulness, thought processes can be slowed, with long lags before answering a question and with slowed processing of ideas. There can be difficulty concentrating and in particular a lack of drive or initiative, with caregivers complaining that a PWP has become more passive. Visuospatial processing can be impaired; this can lead to difficulties with everyday tasks such as driving, dressing or even inserting a hearing aid.

An important part of any discussion with the PWP's doctor is to evaluate how medications may contribute to their symptoms, and to take any steps necessary to simplify the treatment regimen, eliminating those medicines that could worsen thinking difficulties,

such as anticholinergic or sedative preparations. Moreover, PWP with dementia may be particularly prone to confusion and hallucinations as side effects of some of the medications used to treat Parkinson's disease. Second, it is important to distinguish dementia from depression, a common complication of Parkinson's disease. Depression sometimes leads to slowed responses, poor concentration and forgetfulness, and if recognized is amenable to treatment. Third, a number of medications are now in use that

may augment memory and all-round cognitive abilities and their use can be discussed with the doctor.

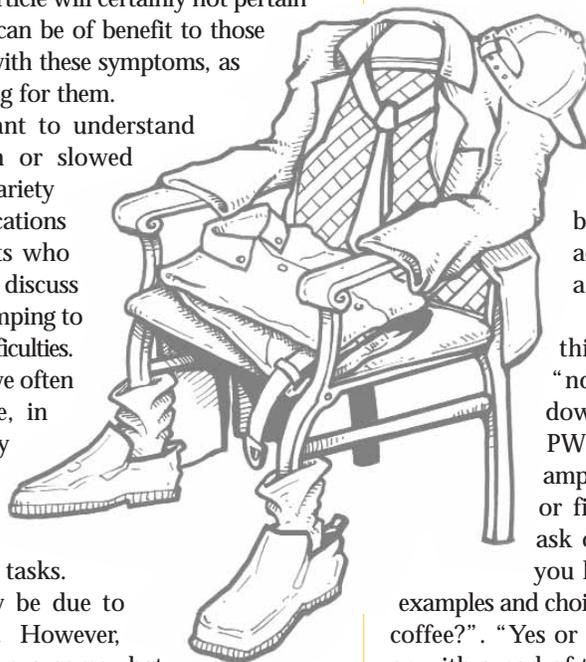
Importantly, there are a number of changes that can be made to help PWP cope with such difficulties, and keeping life simple is the best way of ensuring that he or she will be able to continue to participate in normal activities as effectively as possible, and maintain a degree of independence for as long as possible.

For example, to help overcome slowed thinking, instead of communicating at the "normal" rate, try to make eye contact and slow down your rate of speaking, to ensure that the PWP is able to process everything you say. Leave ample time for their response and avoid interrupting or finishing their sentences for them. Try not to ask open-ended questions such as "What would you like to drink for breakfast?". Instead, provide

examples and choices with closed questions, such as "Do you want coffee?". "Yes or no" answers are easier to give either verbally or with a nod of the head. A simplified home environment can reduce the risk of confusion. Removing clutter and unneeded furniture or little-used kitchen items and appliances is one way of going about this. Another is putting away items you do not want your PWP using.

These include blenders, food processors and sharp knives in the kitchen; ladders, step stools and tools in the garage or basement. Medicines may be kept under lock and key if there is a risk that the PWP may become confused with the doses.

We all know the importance of maintaining a regular exercise regimen. Likewise, mental exercise and activity are important to maintain agile thinking. Exercises can include working crosswords or "seek and find" puzzles, card games, reading or listening to music, keeping a daily diary (also a good memory jogger when



(over please)

reviewed) and pursuing favorite hobbies. Physical activities can also be incorporated — for example, exercising to music or dancing. Again, it is important to realize that these tasks may take much longer to accomplish and patience is a keyword.

For the patient who may have difficulties remembering the sequence of steps to be taken for a particular task, make lists using large print or demonstrate each step so that the PWP can mimic and follow. A “to do” list can be very helpful. For example in the bathroom, a morning list depending on the patient’s abilities/limitations might include:

MORNING ROUTINE

- Brush hair
- Brush teeth
- Flush toilet
- Wash hands
- Turn off light when leaving.

Each step listed should be as simple and straightforward as needed. Remember that these lists may have to become more detailed as time passes. Performing activities of daily living in the same order each day also provides structure and minimizes confusion.

Placing a large calendar in a frequented place (e.g. the kitchen or next to the bed), with appointments or events written in for each day, is another way of helping the PWP to become more independent. This can be reviewed along with a list of tasks for the day on a daily basis.

Another important area to consider is dressing. The message here is to keep it as simple as possible. Have the PWP wear pull-on clothes or clothes that have zippers or only a few buttons in the front, or with Velcro closings. Lay out or stack the clothes in the order in which they should be put on, with socks and underwear on top. If the patient insists on wearing the same thing day after day, buy several identical pieces so you can assure him or her of clean clothes without having to wash them every night.

Make signs on doors utilizing visual and word cues. For example, as well as printing the word “bathroom,” put a picture

of a toilet on the door, or a picture of a bed, as well as the word “bedroom” on the bedroom door.

If mental confusion or hallucinations are present, a dark room can arouse all sorts of scary images. Accordingly, you should consider installing nightlights that automatically go on when a certain level of darkness is reached. This way, your PWP never has to walk into a completely darkened room.

By keeping tasks and questions simple for the patient with thought-processing difficulties, and by preventing situations in which a confused individual can get

himself or herself into trouble, you can eliminate a great deal of the frustration that can arise routinely. And just as important, it can allow the PWP to continue to function and manage parts of his or her own life. This can help with the responsibilities of the caregiver while giving the PWP a sense of accomplishment and involvement in home and life.

It is important to reiterate that memory problems, slowed thinking and confusion do not come automatically with Parkinson’s, to be endured by all. But these problems can co-exist and we believe that the best strategy is to be prepared.

Thanks to the Alzheimer’s Disease and Related Disorders Association (ADRDA) for some of the suggestions mentioned above. Although not specifically for Parkinson’s disease, readers may contact the ADRDA headquarters for further information at: 919 North Michigan Avenue, Suite 100, Chicago, IL 60611 or by phone, (800) 272-3900 or by finding chapter details in a local directory. Further information is also contained in ‘Parkinson’s Disease: A Self-Help Guide’ by Marjan Jahanshahi, M.D., and C. David Marsden, M.D., published by Demos Medical Publishing in 1999. ◻

Jeanne Rosner, Parkinson’s Disease Foundation, and **Claire Henschcliffe, M.D., DPhil**, Center for Parkinson’s Disease and Other Movement Disorders.

10 Tips for Managing Slowed Communication or Thinking

1. Consciously slow your rate of speaking to ensure that the PWP is able to process everything you say, and give ample time for them to respond.
2. Avoid overloading memory processing by asking closed questions that invite “Yes” or “No” answers.
3. Organize daily activities to maintain an active mind, such as listening to music, reading, completing puzzles or making time for hobbies and games.
4. Utilize “to do” lists for daily tasks so that the patient can follow the list to accomplish a given task.
5. Place a large calendar in a frequented place with appointments or events written in for each day.
6. Provide clothing that pulls on or has Velcro closings, arranging them in the order in which they should be put on.
7. Make signs using pictures or objects rather than words and place them on the doors of the corresponding rooms.
8. Medical supplies may be kept under lock and key if there is danger of confusion.
9. Have an ID wrist bracelet or pendant to hang around the neck imprinted with the patient’s name, telephone number and diagnosis.
10. Utilize nightlights if confusion or hallucinations are present to make sure that the PWP doesn’t have to walk into a dark room.