

A DISEASE PROCESS MODULE:

UNDERSTANDING PARKINSON'S DISEASE



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A Disease Process Module:

UNDERSTANDING PARKINSON'S DISEASE

We hope you enjoy this inservice, prepared by registered nurses especially for caregivers like you!

Instructions for the Learner

If you are studying the inservice on your own, please do the following:

- Read through **all** the material. You may find it useful to have a highlighting marker nearby as you read. Highlight any information that is new to you or that you feel is especially important.
- If you have questions about anything you read, please ask your supervisor.
- Take the quiz. Think about each statement and pick the best answer.
- Check with your supervisor for the right answers. You need **8 correct** to pass!
- Print your name, write in the date, and then sign your name.
- Email In the Know at feedback@knowingmore.com with your comments and/or suggestions for improving this inservice.

THANK YOU!

After finishing this inservice, you will be able to:

Name and describe the four main symptoms of Parkinson's Disease.



Name and describe at least six other secondary symptoms of Parkinson's Disease.



Name and describe the five stages of Parkinson's Disease.



Describe at least six ways to help your Parkinson's clients stay safe and be as healthy as possible.



Demonstrate at least three ways to help your PD clients in their daily activities.



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A Disease Process Module:

Understanding Parkinson's Disease

DRIVING WITH YOUR FOOT ON THE BRAKE

Imagine trying to drive a car with your foot jammed on the brake pedal . . .

Will the car move? Maybe a little, depending on how new the brakes are! But movement will be sluggish and jerky.

The car will be hard to handle in turns and on hills. Starts and stops will seem odd, not smooth like the other cars on the road.

This is kind of what it's like to have Parkinson's disease.

People who have Parkinson's disease (also called PD) don't have enough of a chemical called *dopamine* in the brain.

Dopamine is the chemical that tells the brain how to control and coordinate body movements.

When dopamine is low, the brain pulls the brakes on the body's ability to move and control movement. This leaves the person less able to control the body.

Like driving with your foot on the brake . . . movement is sluggish and jerky, difficult to control, and



starting and stopping a movement is not smooth.

PD is a chronic condition which means that it continues over a long period of time. It's also a progressive condition which means that it gets worse as time goes on.

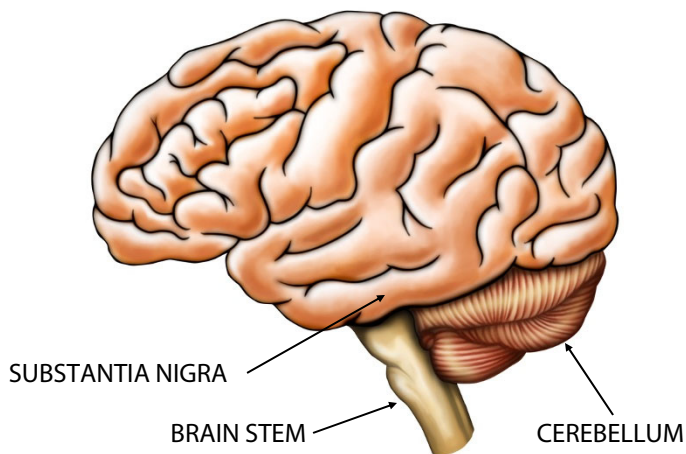
Parkinson's disease affects about one in every 100 people over age 60. The average age at onset is 60, but about 10 percent of sufferers have symptoms as early as 30 years old.

No one really knows the exact cause of PD. There is no test to actually diagnose it, and right now, there is still no cure.

Keep reading to learn more about your clients with Parkinson's disease. You'll learn how to manage the symptoms of PD, what medications your clients may be taking, and how to best help these clients achieve independence and dignity as they face this difficult disease.

ANATOMY AND PHYSIOLOGY OF PD

WHAT'S HAPPENING IN THE PD BRAIN?



There is a small area in the brain stem, just above the spinal cord called the *substantia nigra* (SN). Cells in the SN produce dopamine.

Dopamine is a neurotransmitter that is responsible for regulating movement and balance.

Over time, in people with PD, the cells of the substantia nigra degenerate or die, and therefore no longer produce the dopamine needed for movement and balance. This is why we see loss of control, slowed movements, and tremors.

Symptoms of PD are not present until nearly 80 percent of the SN cells have died. The symptoms may appear minor at first. Then, as more and more SN cells die, less and less dopamine is available to control movement.

Doctors don't know why SN cells die in the first place, and they don't know how to stop it. But, they can replace dopamine with medications to temporarily improve movement and coordination.

SOME TERMS YOU SHOULD KNOW

- **ATAXIA:** Loss of balance and decreased coordination.
- **BRADYKINESIA:** (brady = slow, kinesia = movement) This is a classic symptom of Parkinson's disease. It is the slowing down and loss of spontaneous and voluntary movement.
- **DOPAMINE:** A chemical produced in the brain that helps control movement, balance, and walking. Lack of dopamine is the primary cause of Parkinson's symptoms.
- **DYSKINESIA:** Involuntary, uncontrollable, and often excessive movements that are a common side effect of many drugs used to treat Parkinson's disease. These movements can be lurching, dance-like or jerky, and are distinct from the rhythmic tremor commonly associated with PD.
- **FACIAL MASKING:** A symptom of Parkinson's, in which the face appears frozen like a mask, without expression and with reduced blinking.
- **FREEZING:** Abrupt and temporary inability of Parkinson's patients to move that frequently occurs at a boundary such as a door or when exiting a car.
- **NEUROTRANSMITTER:** A special chemical messenger (like dopamine) that sends messages from one nerve cell to another. Most neurotransmitters play different roles throughout the body, many of which are not yet known.
- **PILL-ROLLING:** Alternating movements of the thumb and forefinger that give the appearance of rolling a small object between the fingers; a characteristic, slow tremor in the fingers of Parkinson's patients.

WHAT'S NEW?

Grab your favorite highlighter! As you read through this inservice, **highlight five things** you learn that you didn't know before. Share this new information with your supervisor and co-workers!



WHAT CAUSES PARKINSON'S DISEASE?

ENVIRONMENT OR GENETICS?

No one really knows what causes Parkinson's disease. Doctors and researchers have managed to figure out **what** goes wrong in the brain, but they don't know **why** it goes wrong. If they can figure out the cause, then they may be able to find a cure.

Even though, researchers don't know why PD happens, they have a few theories as to what causes it. Some say PD is caused by a defective gene that can be inherited and therefore seen in several generations of family members.

Over the past 10 years, there have been several isolated families found to have Parkinson's because of a *defective gene*. But, this has been found to be only a small percentage of the overall PD population. A vast majority of PD sufferers do not have the defective gene.

Other researchers believe there is an environmental reason for the disease and have proven exposure to certain drugs or chemicals can create the symptoms of PD.

One of the most important clues toward finding the cause of Parkinson's disease was discovered because of illegal drug use! In the late 1970s and early 1980s, several heroin addicts injected themselves with a homemade drug which caused permanent Parkinson's disease symptoms.

Another argument for the environmental connection is a strong link between the risk of PD and living in a rural area. It seems exposure to well water and farms, which increases exposure to pesticides or herbicides may cause or contribute to PD. However, these factors alone do not automatically cause rural residents to develop PD, just as their absence does not protect against it.

Today, most researchers believe there is a combination of genetic and environmental factors that cause Parkinson's Disease.



WHAT excites YOU?

You don't have to be a physician or a scientist to provide some real symptom relief to your clients with PD. Here are a few suggestions that may help!

Massage: Massage reduces muscle tension and promotes relaxation, which can be especially helpful to people experiencing muscle rigidity associated with PD.

Tai chi: (pronounced TY-CHEE) This is an ancient form of Chinese exercise with slow, flowing motions that helps improve flexibility and balance. Tai chi can be tailored for people of any age or physical condition. Check the phone book or search the web for Tai Chi classes offered in your client's community.

Yoga: Yoga is another type of exercise that increases flexibility and balance. Many community centers and senior centers offer modified yoga classes for people who are older and possibly less flexible.

Check around, ask questions, and talk to your client about these safe and natural therapies!

HOW IS PARKINSON'S DISEASE TREATED?

So far, **there is no cure** for Parkinson's disease. But, there are many medications that can help the symptoms. It is important to remember, though, that each client reacts differently to these medications.

The most common medications (called anti-Parkinson's drugs) are Sinemet, Elderpryl, and L-Dopa. They are short acting and must be spaced in small doses throughout the day.

These drugs are very powerful and can have many side effects.

Anti-PD drugs can cause an "on-off" syndrome. One moment the client seems fine and the next moment he or she has trouble walking or talking. This is because the medication is wearing "off." To fix this problem, doctors usually increase the medication dose.

Clients who do not respond well to medications may opt for a surgical intervention. Over the past 50 years, surgical options called pallidotomy and thalamotomy were widely used to treat severe Parkinson's symptoms. However, these surgeries caused lesions (areas of damage) to the brain that were irreversible.

Today, those surgeries have been replaced by a procedure called **Deep Brain Stimulation** (DBS). In DBS, a transmitter is placed in the upper chest, like a pacemaker. But, instead of connecting to the heart, the DBS device connects to an area in the brain. The DBS device delivers a small electric current to the brain which increases the activity that has been decreased by the lack of dopamine.

DBS has become more widely used because it is not permanent like the previous surgeries were. If complications occur, the device can be removed.

The most frequent complication with DBS is infection immediately after the procedure. If this happens, the device can be removed and replaced at a later time.

Most people with DBS go back to their normal lives and report at least 4.6 hours more "on" time than those on medication alone. This means they have nearly 5 more hours of tremor-free time during the day!



THINK about it!

You might think the hottest topic surrounding Parkinson's disease is the issue of stem cell research . . . but it's not. The touchiest topic is actually about **driving** with Parkinson's disease.

Driving represents freedom and independence and those are hard rights to give up. But, the reality is PD clouds judgment—making it difficult for clients to even realize their driving is impaired or even dangerous.

Slowed reaction times, muscle stiffness, and the inability to judge distances all contribute to unsafe driving.

- **So, how do you know when it's time to take the keys away? And, what is the best way to do it?**
- **Share your thoughts and ideas on this matter with your co-workers and supervisor.**

"You've probably read in People that I'm a nice guy - but when the doctor first told me I had Parkinson's, I wanted to kill him."

~ Michael J. Fox



THE FIVE STAGES OF PARKINSON'S DISEASE

One of the most common evaluation scales for Parkinson's disease clients is the Hoehn-Yahr scale. According to this scale, there are five stages of Parkinson's disease. They are:

- **Stage 1**—Symptoms are very **mild** and annoying. They are usually on **one side of the body**.
- The client's family and friends have started to notice some changes in posture, walking, and facial expression.
- **Stage 2**—Symptoms begin to affect **both sides of the body** and they are more **obvious**.
- The client's posture and walking are affected. Minor signs of disability are starting to show.
- **Stage 3**—Symptoms are **very obvious**. The client's balance and walking are affected a lot.
- Standing is a problem, too. The general coordination of the client begins to fail.
- **Stage 4**—Symptoms are more **severe**. The client can still walk, but not very well.
- Stiffness and slowness are a big problem. Many clients become unable to live alone.
- **Stage 5**—Symptoms are **disabling**. The client is unable to walk or stand. They become completely dependent on others and require constant care.



Think about the clients you care for (or have cared for in the past) who suffer from symptoms of Parkinson's disease.

- If you have cared for a client with Parkinson's disease, what stage do you think that client was in? What makes you think that?
- What type of treatment does your PD client receive (medication/DBS/physical therapy)?
- What did you have to do differently to help your PD client stay active and independent?
- What will you do differently after completing this inservice?
- What would you do if you noticed signs of Stage 1 in a client NOT diagnosed with PD?

TAKE IT A STEP FURTHER: *Clients with PD may become agitated or angry when they cannot control their tremors. Tremors can also lead to poor sleep which can make matters worse. How would you handle a client who becomes angry or agitated? Share your ideas with your supervisor and co-workers.*

Each stage of Parkinson's can last for many, many, many years!

MAIN SYMPTOMS OF PARKINSON'S DISEASE

There are four main symptoms of Parkinson's disease. They are:

- **Tremor** (Shaking)
- **Rigidity** (Stiffness)
- **Bradykinesia** (Slowness)
- **Postural Instability** (Unsteadiness)

1. TREMOR (*SHAKING*)

- Tremor is also called Resting Tremor because it's most noticeable when the client is at rest.
- It usually begins with the hands and feet, but can affect the head, neck, face, tongue, lips, and jaw.
- The shaking or trembling is at a regular beat of around four to six beats every second. It may happen only on one side of the body or it could be worse on just one side depending on the time of day.
- Stress can make it worse.

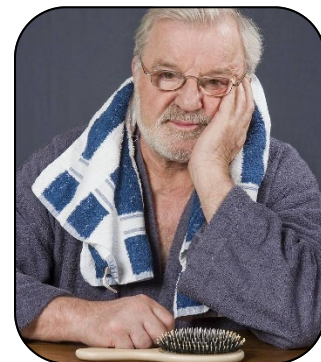


2. RIGIDITY (*STIFFNESS*)

- Rigidity is a stiffness or an ache in the muscles. The muscles are always tense and it gets worse with movement.
- This happens to all the **voluntary** muscles. So, it's hard for a PD client to move their arms and legs. Their arms don't swing when they walk.
- Parkinson's clients can have trouble with breathing, eating, swallowing, and speech, too.
- The face loses expression and becomes "mask-like." The eyes don't blink as often, and it's hard to smile.

3. BRADYKINESIA (*SLOWNESS*)

- This symptom is about slow movement.
- It's very frustrating for people with PD because it takes them a very long time to do routine things like walking, bathing, eating, and dressing.
- They move in slow motion. And to make it worse, they never know when it will happen. One minute they seem to be moving fine and the next minute, they aren't.



Everyday tasks such as dressing and bathing can take several hours!

4. POSTURAL INSTABILITY (*UNSTEADINESS*)

- This term means loss of balance or unsteadiness.
- People with Parkinson's disease lose their coordination and fall down easily.
- They tend to lean forward or backward especially when they walk. They tend to have poor posture and can have droopy shoulders and a lowered head.

A REMINDER

As you work with PD clients, always remember to report any changes in symptoms to your supervisor! Even something very minor like slurring of words can be very, very important.

OTHER SYMPTOMS OF PARKINSON'S DISEASE

There are many other symptoms of Parkinson's disease. They are called **secondary symptoms**. Sometimes the disease causes these symptoms and sometimes they are caused by the anti-Parkinson's drugs!

CHANGES IN MOTOR SKILLS:

Walking Problems

- People with PD often have a slightly bent posture, shuffling of feet, and lean forward when walking.

Freezing

- This is a sudden stop in movement, mostly in walking.
- Like "freezing in one's tracks."

Falling Down

- Falls usually happen because of a loss of balance either while walking or *from any sudden movement*.

Writing Difficulties

- Common problems include handwriting that looks cramped, spidery, and becomes very small.



Speech Problems

- People with Parkinson's disease often struggle with slurring words, repeating words, talking too fast, talking too slow, and/or talking too soft.

CHANGES IN EMOTIONS

Depression

- A common problem in people with Parkinson's—can be mild or serious.
- *Signs* of depression include weight loss or gain, lack of energy, overwhelming feelings of sadness, anxiousness, sleeping more or less than usual, loss of interest in usual activities, and thoughts of suicide.

Emotional Changes

- Common feelings include embarrassment, insecurity, and fear.

Sleep Troubles

- Nightmares and restless sleep are common.
- Some PD clients may be drowsy during the day and have a difficult time getting to sleep—and staying asleep—at night.

Mental Confusion

- Includes loss of memory and slow thinking that may get worse over time.
- Changes in behavior and personality are common. So are hallucinations—they're almost always related to anti-Parkinson's medications.

Dementia

- This serious decline in memory, thinking, and behavior is most common in PD clients over age 70.

A FEW INTERESTING FACTS:

About 30% of all people with Parkinson's have some degree of dementia.

About 25% of PD clients experience hallucinations from PD medications.

Falling down is one of the most serious consequences of Parkinson's Disease.

50% of all Parkinson's clients have speech troubles!

Some research has found that over 50% of people with PD experience periods of depression.

OTHER SYMPTOMS OF PARKINSON'S DISEASE

Swallowing Problems

- Often an issue during the *late* stages of Parkinson's.
- Food and saliva collect in the mouth which results in drooling and choking.

Constipation and Urinary Difficulties

- Both rigidity and slowness of movement affect the bowel and urinary muscles.

Sexual Difficulties

- Caused by a combination of normal aging, use of anti-Parkinson's medications, and the disease itself.

Vision Problems

- Common problems are blurred vision, difficulty reading, and occasional double vision
- Sometimes the medications cause blurry vision.

Nausea

- Queasiness and loss of appetite are common side effects of anti-PD medications.
- Stomach muscles can be affected by the disease, too.

Involuntary Movements (Dyskinesia)

- Dyskinesia includes jerky arms and legs, twitching, facial grimacing, and swaying. It's usually a side effect from anti-PD drugs.

Dizziness

- Caused by really low blood pressure due to anti-Parkinson's medications.
- Also, certain nerves are affected by the disease and cause lightheadedness.

Pain

- Caused by a combination of PD and its medications— it ranges from mild to severe.
- The pain may include muscle cramps, spasms, stiffness, numbness, tingling, tightness, achiness, and burning sensations.



5 KEY points

Key Points to Remember

1. Parkinson's eventually affects every part of the body and mind.
2. There is no cure for PD but medication or surgery can ease the symptoms.
3. When caring for a client with PD, your goal should be to encourage independence for as long as possible . . . even when it seems to take forever for your client to perform simple tasks!
4. It can be very frustrating for clients with PD to suddenly lose the ability to care for themselves. Never take an anxious or angry outburst personally.
5. Clients with a chronic disease like Parkinson's, for which there is no cure, may become depressed, withdrawn, and even suicidal. **Be sure to report any signs that your client is becoming depressed or suicidal immediately so intervention can be initiated.**

"The war against Parkinson's is winnable. And you can play a part in the victory."

~Michael J. Fox

TIPS FOR HELPING CLIENTS WITH PD

HELPING WITH MEDICATIONS

- Remind your clients to take their medications **ON TIME!!!** Many PD medications are short acting and must be taken at certain times to help prevent the “on /off effect.”
- Help your clients remember when to take their medications. You can suggest they use a watch or pill box with an alarm. Help them set the alarm to the proper times.
- Encourage your clients to always carry a day's dosage of medication with them at all times. Parkinson's clients should **never** be without their medication!
- Remind your clients to always take their medications as prescribed by their doctor—no *more* and no *less*.
- If a client mentions to you that he/she is going to skip a dose of medication, alert your supervisor immediately!
- Encourage your clients to **move around** after they take their PD medication. It will help with digestion and absorption of the medications.
- Suggest a warm bath, now and then, rather than a shower. Warm baths may help the medication work more quickly.
- Encourage your clients to drink lots of water with their medications.
- Suggest eating an oatmeal cookie or drinking ginger ale when taking medications. This may help control nausea.
- Be alert! Many anti-Parkinson's medications cause side effects that make symptoms of PD **worse**. A change in symptoms may mean your client is getting the wrong amount of medication. Let your supervisor know right away!
- If you notice that your client is mixing their anti-PD medications with other prescription and/or over-the-counter medications, let your supervisor know immediately!



Working with clients in the home often requires coming up with creative solutions to common problems.

- **THE PROBLEM:** You are caring for a 74-year-old man with PD.
- He has tremors and trouble walking, but usually responds well to his medication and can get most of his ADLs done with very little help.
- On this day, the medication doesn't seem to be working and he is becoming frustrated while trying to get washed and dressed.
- **WHAT YOU KNOW:** You know PD is progressive so you expect symptoms to get worse as time goes on, but this is a drastic change in your client.
- You report the behavior to the nurse who agrees to assess the situation.
- **GET CREATIVE:** Think of **three creative solutions** you might try right now to help your client get washed and dressed without further frustrating him.
- **TALK ABOUT IT:** Share your ideas with your co-workers and supervisor and find out how they would solve the problem.

MORE TIPS FOR HELPING CLIENTS WITH PD

HELPING WITH NUTRITION

- Eating well-balanced meals is very important. Encourage your clients to eat properly. You may have to serve your clients soft foods and cut up their meat into small pieces because tremors and swallowing problems will make eating more difficult and time consuming.
- **Don't** rush your clients during meal time! Remember that it can take a long time for people with Parkinson's to do the simplest tasks because of slowness of movement. It's very important to allow them plenty of time to eat so that they will be well-nourished.
- If you cook for your client, do your best to include foods high in fiber to reduce constipation, and foods high in vitamin D and calcium to help prevent loss of bone density. Also, do your best to cook foods low in protein. Too much protein may get in the way of the body fully absorbing PD medication.
- Staying hydrated is also important. Encourage your clients to drink plenty of fluids (at least 8 cups every day) even in the winter.
- If your client has trouble with a dry mouth, suggest they *limit* coffee, sodas and citrus juices.



- Exercise should be fun! After checking with your supervisor, try exercising with your client. It's good for you, too. Take a walk around your clients home, within your facility, or even outside. If a pool is available, try some water exercises because they are easier on the joints.
- Remind your clients to *pace* themselves! Don't do too much all at once. To prevent fatigue, try several short exercise sessions throughout the day.

HELPING WITH ENERGY CONSERVATION

- Your clients will have good days and bad days. On a good day, your client may be full of energy and feeling pretty good. There will be a tendency to do way too much! Remind your clients not to overdo it so they won't be tired the next day.
- Fatigue is a big problem for people with PD. Encourage your clients to take lots of rest breaks throughout the day.
- Be patient! PD clients can take a long time to do everyday tasks. Rushing them can cause stress and that could make the PD symptoms even worse—and may actually slow your client even more!
- Be encouraging! If your PD clients become frustrated or irritated that everything they do seems to take so long, respond with some humor and pretend that **you** have all the time in the world. This may help them to relax and then they may be able to move around a bit better.
- If your PD client is having a bad day, encourage your client to save some activities for another day. Help them decide which tasks are the most important to do that day.

HELPING WITH EXERCISE

- Check with your supervisor about encouraging your clients to get regular exercise. Physical activity improves general health and emotional well-being. And it will help keep your PD clients flexible and strong so that it's easier for them to move around.

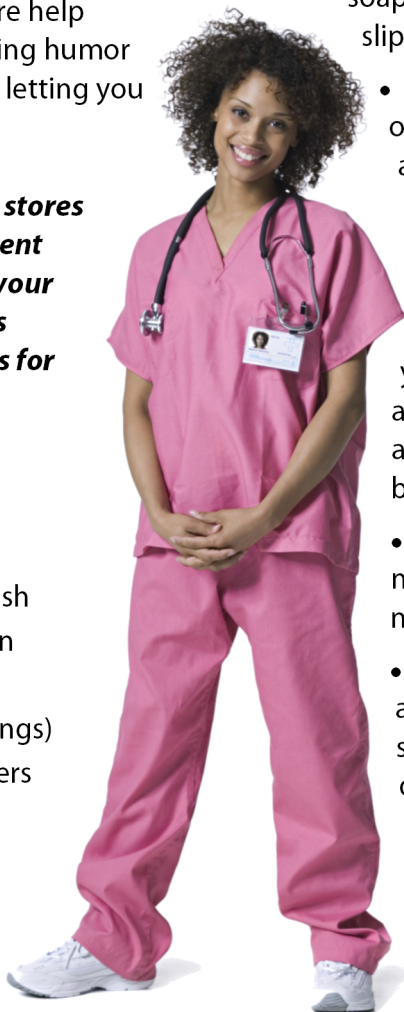
MORE TIPS FOR HELPING CLIENTS WITH PD

HELPING WITH PERSONAL CARE

- On a day when things aren't going well for your PD clients, you may want to give them extra help with their personal care. For female clients, offer to fix/style their hair or paint their fingernails. For male clients, offer to help them shave or clip their nails.
- If your PD clients suffer from leg cramps, you can offer to massage their legs.
- To help with muscle spasms, you may want to suggest taking a warm bath instead of showering. But be sure to help your PD client get in and out of the tub!
- Some PD clients may need more help than they think they do. Try using humor or tell a story to coax them into letting you help.

There are many items available in stores that may help your Parkinson's client remain independent. Check with your supervisor and/or family members about getting some of these things for your client!

- Hand-held showerhead
- Soap on a rope.
- Electric toothbrush
- Long-handled toothbrush
- Long-handled shoe horn
- Dressing sticks
- Grabbers (to pick up things)
- Velcro strips and fasteners
- Raised toilet seat
- Satin sheets
- Shower bench
- Button hole helper
- Big handled utensils



HELPING WITH SAFETY

- To help your PD clients avoid trips and falls, suggest that they remove "throw" rugs from entrance ways, bathrooms, and kitchens.
- If you work in client's homes and they don't have grab bars, suggest to them that it's a good idea to get them. If they lose their balance, they will have something **sturdy** to grab! If you work in a facility and they don't have them, talk to your supervisor right away!
- Check to see if your PD clients have non-skid strips or mats in their tubs and showers. They help prevent slips and falls. Be careful, though...if soap residue builds up, the mats can be just as slippery as the tub or shower!
- If your PD clients are unsteady on their feet or need to rest often, suggest a shower bench and a hand-held showerhead. They can take a "sitting down shower." If you see your clients in a facility and they don't have these, talk to your supervisor right away!
 - A raised toilet seat may be helpful to your PD clients. It provides easier and better access to the toilet. It's even better if it has armrests to help your clients keep their balance and to prevent falls.
- Encourage your clients to have lots of night lights in their rooms and homes for nighttime trips to the bathroom.
- Help your PD clients keep their rooms and homes free of clutter to help prevent slipping and falling. And clutter makes it difficult to use walkers and wheelchairs.
- Most people with PD have trouble holding onto things, so encourage your PD clients to use paper plates and cups. If they drop them, they won't break and cause injury.



A Disease Process Module:
Understanding Parkinson's Disease

EMPLOYEE NAME
(Please print):

DATE: _____

- ***I understand the information presented in this inservice.***
- ***I have completed this inservice and answered at least eight of the test questions correctly.***

EMPLOYEE SIGNATURE:

SUPERVISOR SIGNATURE:

Inservice Credit:

<input type="checkbox"/> Self Study	1 hour
<input type="checkbox"/> Group Study	1 hour

File completed test in employee's personnel file.

Are you "In the Know" about Parkinson's disease? Circle the best choice or fill in your answer. Then check your answers with your supervisor!

- True or False**
Dopamine is a neurotransmitter responsible for movement and coordination.
- Fill in the Blank**
Abrupt and temporary inability of Parkinson's patients to move is known as _____.
- True or False**
Researchers believe Parkinson's is mainly caused by a defective gene.
- Fill in the Blank**
DBS involves implanting a device (like a pacemaker) into the chest that sends electrical waves to the _____.
- At which stage of PD does the client usually become unable to live alone?**
A. Stage 2. C. Stage 4
B. Stage 3 D. Stage 5
- True or False**
It doesn't matter what time your PD client takes his medication—he just has to remember to take it every day.
- Fill in the Blanks**
If you cook for your client, do your best to include foods high in _____ to reduce constipation, and foods high in vitamin D and _____ to help prevent loss of bone density.
- True or False**
If your client freezes while walking, you should pull on an arm to get the movement started again.
- True or False**
A shower chair and handheld shower head can help with safety and fatigue.
- True or False**
Both rigidity and slowness of movement can lead to constipation and urinary problems.

