CAREGIVING TIPS FOR PATIENTS WITH PARKINSON'S

Parkinson's disease is a brain disorder that occurs when nerve cells in the brain break down. This means that the body makes movements on its own, without regard for how a person wants his or her body to move. The most common symptom is called tremor – the involuntary shaking of limbs. Other symptoms include problems with balance, stiffening of muscles, difficulty swallowing, drooling and trouble speaking. Since these symptoms progress over time and are very public, it is very common for Parkinson's patients to suffer from depression and/or anxiety.

Generally speaking this disease afflicts seniors. Only 15 % of diagnoses occur with people under the age of 50.

The primary treatment for Parkinson's is medication; however this condition also requires the active involvement of the patient, the family and the caregivers to reduce the impact of the symptoms and to allow the patient to function as normally as possible.

A Personal Care Manager can assess the progression of the patient's condition and recommend appropriate resources, activities and approaches. Following are a range of factors associated with Parkinson's. Although they are presented separately, many are inter-related. The goal is to maintain the patient's function for as long as possible. A secondary goal for caregivers is to support the family as they help to manage the daily activities of the elderly person.

EXERCISE AND ACTIVITY

Because common symptoms of Parkinson's include stiff limbs and exhaustion, it is very useful for a patient to meet with a Physical Therapist (PT) and an Occupational Therapist (OT).

The PT will develop a set of exercises that can reduce limb stiffness.

- Resistance training and aerobic exercise may improve the ability to function, including balance and ability to walk. There is new research that suggests that exercise also may prevent the degeneration of nerve cells associated with Parkinson's.

The OT can teach the patient way to make normal activities easier and safer.

- Adaptive devices such as handholds in the bathroom and bannisters in the stairway.
- Getting out of chairs can be made easier with a cane or other adaptive device.
- An OT can also teach the patient to conserve energy by grouping activities in certain locations placing things needed – like reading materials, glasses, the phone – in an area close they sit.

NUTRITION AND DIET

Since the ability to swallow is adversely affected by Parkinson's, diet can play a positive role not so much because of the actual nutrients as the physical consistency. (It is interesting to note, however, that eating apples – particularly red apples – may protect against Parkinson's, because they contain a certain flavonoid associated with protecting brain cells.)

Respiratory infections occur because aspiration of food and fluids can lead to pneumonia and malnutrition.

Urinary tract infections may result from urinary retention and inadequate food intake.

Constipation is a common gastrointestinal problem resulting from a lack of bulk-type foods and fluids.

Problems swallowing can lead to anorexia. This and nausea is also a side effect of the medications.

Finally difficulties swallowing are exhausting.

Solutions to these problems include:

- Serving milk shakes, juices in gelatin form or any other thicker drinks
- Semi-solid foods like pudding and foods with high water content like fruits
- Ensuring foods are soft and/or moist
- Foods with crumbs – like crackers or cakes – should be avoided as these may get caught in the throat
- Caregivers should encourage patients to eat very small bites and to chew food thoroughly before swallowing
- Sipping a drink and keeping it in the mouth while preparing to swallow will moisten food.

TREMORS

Unfortunately, there is little that can be done, outside of medication, to reduce the tremors that are readily associated with Parkinson's.

- Try reducing the intake of products containing caffeine – coffee, tea, colas.
- It's possible to put on a rigid brace over the joint and then placing some weight on the hand will decrease the tremor and even restore content.

DROOLING

A particularly unfortunate symptom of Parkinson's is drooling caused by the loss of voluntary muscle control.

- Since sugary foods increase saliva, patients should not been given foods with sugar in them
- Caregivers should encourage patients to keep their lips closed when not eating or speaking
- A PT can suggest lip exercise that may help strengthen the muscles in the lips

FALLS

A person with Parkinson's tends to be physically unstable which means that injury from falls is common.

- Many falls can be prevented by the use of a cane or walker.
- A home safety inspection should be conducted and safety devices such as bathroom handholds should be installed.
- Floor coverings and furniture should enable a barrier-free route for walking.
- Shoes that fit well, are lightweight, support the foot and do not cause either slipping or too much friction are needed.

COMMUNICATION

Many people with Parkinson's have communication challenges. This can be due to the lack of muscle control and or to the periods when their meds wear off. They often are not able to use facial expressions to support their feelings or to speak clearly and/or quickly. This can lead to internal frustration or anxiety which exacerbates the communication difficulties.

Following are some communications tips:

- Try to speak slowly and clearly with short sentences and simple ideas.
- Be sensitive to the tone of your voice and do not telegraph impatience of frustration
- Choose times when the meds are working to have important conversations
- Give the patient time to respond
- Show them you are engaged by (where appropriate) nodding your head, touching their arm or maintaining eye contact
- Use hand and eye movement to reinforce your words
- Ask for feedback if you are not able to read their facial expressions
- Take notes of your conversations and record any observations

Consider bringing in a speech pathologist for assessment and suggestions for improving communications skills

DEPRESSION AND ANXIETY

Because the disease is progressive and because its symptoms are so visible and invasive, it is very common for the patient to suffer from depression and/or anxiety symptoms. Medications are a frequently used tool to deal with this. But there are also steps that a caregiver can take, including:

- Encourage them to exercise, as exercise helps lift a person's spirits and gives them a sense of control over their body
- Exercise recommended by a PT or OT can help reduce symptoms by keeping the muscles limber
- Relaxation techniques can help with anxiety and may even help boost the immune system (thereby delaying progression)

- Note when any medications are starting to ear off and schedule activities around this time to maintain physical and social function.

- Encourage the patient and their family to become involved in Parkinson's support groups. This will both make them feel less different and alone and may generate other coping suggestions. There are usually Parkinson's Societies in major centres.

DISEASE PROGRESSION

Because Parkinson's is a progressive disease, the changes can sometimes be subtle as they occur over time. Following are a series of questions that a caregiver can use to track changes. It's recommended that this assessment be conducted every 6 months, noted on the Progress Report and, where appropriate, shared with the Nurse Manager and family.

- Is the patient tired most of the day?
- Do they complain of numbness, tingling or aching?
- Are they often constipated?
- Do you notice changes in their thinking, e.g., solving problems or remembering things?
- Are you having difficulty understanding them when they speak?
- Do they have problems swallowing or choking on their food?
- Do they suddenly doze off or zone out while engaged in an activity such as eating or having a conversation?
- Has their handwriting changed in the last 6 months?
- Have they had a fall down in the last 6 months? If so, how many times?
- Do they freeze or stop suddenly when walking?
- Are there changes in their ability to drive the car?
- Have they had violent dreams?
- Do they feel sad for several days at a time?
- Do their medications take a longer time before they start working?
- Do they work for a shorter period of time?
- Do they have urinary problems?
- Do they feel light-headed or dizzy when they get up from a chair or bed?
- Do they want to go shopping more often or have a keen desire to buy lottery tickets?
- Have they noticed a change in their sense of smell?

If you or someone you know is challenged with Parkinson's disease, please contact us for more information.

Special thanks to the Parkinson Society Canada for much of this information