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Joaquim Ferreira
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THE **PARKINSON'S DISEASE** CAREGIVER'S HANDBOOK

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Joaquim Ferreira
Marli Lopo Vitorino

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EDITORS

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PREFACE

This handbook is part of a series of educational initiatives intended for caregivers and family members of people with Parkinson's disease.

It has been written by health professionals from different areas, all with experience in caring for people with Parkinson's disease. We have chosen to address this book to caregivers and family members, as their role is often neglected.

With this handbook we hope to answer questions caregivers may have and to fill-in the information gaps. Unfortunately, most of the available information on Parkinson's disease is either intended exclusively for health professionals or focused just on patients.

With concise and accessible texts, we hope that this handbook will help all of those directly involved in caring for anyone with Parkinson's disease.

MD, PhD. JOAQUIM FERREIRA

MVitorino

MARLI LOPO VITORINO (nurse)

01.WHAT IS THE ROLE OF THE CAREGIVER?

Marli Lopo Vitorino, *Nurse*

Parkinson's disease (PD) is a chronic neurodegenerative disease that inevitably changes the life of both the patient and their family. As the disease progresses, the patient becomes progressively more dependent on others in carrying out daily tasks.

This difficulty is due to the motor limitations caused by the disease as well as to the non-motor problems such as sadness, behavioural changes, pain, dizziness, etc.

In this sense, caring for someone with PD can be a long and arduous journey, requiring the caregiver to be available, dedicated, and having the knowledge to take good care of the patient. As PD is a complex, fluctuating, and often unpredictable disease, it is important for caregivers to have an understanding of the illness, of how it may change the patient, the possibilities for treatment, and on the availability of professional help. This knowledge is essential for the caregiver to feel confident and able to care for the person with PD, while avoiding physical and psychological exhaustion.

Being a caregiver, particularly when the person with PD is a family member or friend, is not always a choice. Indeed, caregivers are usually family members, friends, neighbours, or community members. The role of the caregiver is not only to carry out tasks for the person with PD, but also to accompany and help them carry out daily activities at their own rhythm.

The caregiver's role is fundamental in improving the quality of life of the person with PD. It involves helping gradually adapt routines and avoiding social isolation and/or early institutionalization. Caregivers are responsible for very specific care that includes:

- Being a connection between the person with PD, the family and health professionals;

- Listening and helping the person to express their feelings and fears. Not only is there is no cure for PD but also it follows a progressive course, i.e. symptoms worsen over time, which can cause feelings of frustration, anger, sadness, depression, and isolation;

- Promoting tasks that stimulate the brain (sociocultural, leisure, or other appropriate occupations);

- Complying with strict medication adherence as prescribed—medication may be required at specified times and at very close intervals;

- Ensure adequate and safe eating—one of the most severe complications of PD is choking. It may be necessary to use specific strategies to prepare and deliver food/liquid safely;

- Helping with locomotion and physical activities (walking, sitting, getting up, and lying down)—imbalance and difficulty moving increase the risk of falling;

- Providing information to doctors and other health professionals about health status, reactions to medication and treatments, mood and other problems (e.g. dizziness, sleep problems, difficulty walking, falls, weight loss, constipation, etc.).

In addition, the caregiver must be available to provide attention, support, motivation, and peace of mind. The caregiver has to interpret and analyse the gestures of the person with PD, understand their fears and doubts, know when to encourage them to surpass themselves or adapt to their new limitations.

In order to be able to take good care of people with PD, the caregiver must be physically and psychologically fit. Fear and anxiety can aggravate the condition of a person with PD, and it is important that the caregiver remains calm, confident and receptive to the help of health professionals and support groups in their community. These groups can help with counselling, clarifying doubts, sharing experiences, and providing information, thereby helping to avoid social isolation and exhaustion.

02.WHAT IS PARKINSON´S DISEASE?

Anabela Valadas, *Neurologist*

Parkinson´s Disease (PD) is a movement disorder, which means that it mainly affects the way people control their movements as well as how they actually move. Important changes occur in the brain of people with PD, which will lead to the onset of various symptoms.

One of these major changes is related to the progressive death of neurons, cells that make up the brain, in a region called the *substantia nigra*. In this brain region neurons produce a chemical substance called dopamine, which is responsible for the transmission of messages between different areas of the brain that control the way we move. It is, therefore, the progressive loss of dopamine that is responsible for the motor symptoms that we observe in a person with PD: these include bradykinesia (slowness of movements); tremor (usually more prominent on one side of the body, more frequent in the fingers and at rest); stiffness (increased resistance when trying to mobilize a joint); and postural instability (responsible for imbalance and falls).

We do not know what causes the death of dopamine-producing neurons in PD. However, individuals who have a particular set of characteristics are at a greater risk of developing PD. Having these risk factors does not necessarily mean that a person will develop PD. These risk factors are: age (the single most important factor as PD is more frequent in the elderly); being a man, as they have a slightly greater risk than women; genetics, which means that alterations in specific genes have been identified as causing PD, though such alterations are rare. Genetics are more likely to be implicated in PD in those who develop the disease at a younger age and in families where several members have been affected by PD.

In addition to the symptoms concerning movement, people with PD have other complaints unrelated to the way they move, which are called non-motor symptoms. In the brain there are other changes responsible for these complaints. In most cases they are related to the deposit of a substance called alpha-synuclein. This substance exists in the brain but in PD, for reasons that are unknown, it becomes insoluble and starts to deposit and aggregate into clusters which are known as Lewy bodies. The various non-motor symptoms arise depending on the areas of the brain affected by Lewy bodies. The areas more frequently involved are those responsible for smell and sleep, and therefore these are the most frequent non-motor symptoms seen in people with PD.

Alpha-synuclein has also been found deposited at sites outside the brain, namely on the wall of the gut, resulting in frequent complaints of constipation.

Therefore, the complaints of people with PD occur in relation to these changes in the brain. In order to stop the progression of the disease a large body of research is currently under way. This aim has not yet been achieved: PD does not have a cure and its progression cannot be stopped, however, there are many treatments available such as medication, surgery, and rehabilitation, which are efficacious in controlling motor and non-motor symptoms in people with PD.

03.WHAT ARE THE MAIN COMPLAINTS OF PATIENTS WITH PARKINSON'S DISEASE?

Miguel Coelho, *Neurologist*

Several complaints may lead the patient with Parkinson's disease (PD) to consult their physician for the first time before diagnosis. PD may manifest in different ways and with different features, and each patient and their family experience symptoms differently.

However, as a rule, slowness, tremor, or both, are the main complaints leading patients to consult with a physician. Symptoms start insidiously and progress slowly; only in rare cases do they start suddenly. PD symptoms, such as rigidity, less arm swing, or slowness of a leg, usually start on one side of the body and later progress to the other side, although one side will always be more affected than the other.

SLOWNESS OF MOVEMENT

Slowness of movement is the defining feature of PD and the leading complaint of patients. It manifests in several ways, such as a change in handwriting that becomes smaller and slower and difficult to read. It may also appear as a difficulty in performing fine motor gestures such as shaving, buttoning, eating, using a key, or wearing earrings. Nevertheless, patients can feel objects well and have normal strength despite this slowness. Family and friends will notice that the PD person's face is less emotive like a "poker face", the patient seems sad, and speech is less understandable. Patients complain that they shuffle one leg, walk slowly with small steps, and in some instances, they will even stumble on carpets or pavements, but falls are rare in early disease stages. Patients may mention having more difficulty walking side by side with their relatives or friends and may experience difficulty rolling over in bed at night, or say they wake up in the same position they fell asleep in.

TREMOR

Tremor is the most frequent symptom at the onset of PD. Usually, it affects the hand or foot on one side of the body, and occurs at rest (rest tremor), improving when performing any task, and less frequently it takes place during actions such as eating or holding a cup. It embarrasses patients, although it usually does not interfere with performing actions or with walking. It disappears during sleep. Chin tremor can also be present, but head tremor is not a feature.

03.WHAT ARE THE MAIN COMPLAINTS OF PATIENTS WITH PARKINSON'S DISEASE?

Miguel Coelho, *Neurologist*

OTHER COMPLAINTS

It is frequent, although not mandatory, that patients will mention other complaints when consulting a physician for the first time. A few of these complaints have been present long before tremor or slowness, but patients may only realize their presence when the physician asks about them.

Some will notice their sense of smell is worse, while others complain of nightmares. The partner may mention that the patient has started acting out their dreams during sleep, often with violent movements of arms or legs or loud noises. These movements may hurt the partner or the patient him/herself if a limb hits an object. In other instances, constipation may be a new problem. Sadness and/or a loss of interest in performing usual hobbies or duties can be a non-motor manifestation of PD and may be the first reason that leads the patient to consult a psychiatrist.

STAY TUNED

04. IS PARKINSON'S DISEASE HEREDITARY?

Leonor Correia Guedes, *Neurologist*

Although in the large majority of people with Parkinson's disease (PD) (around 90% of cases) the cause of the disease remains unknown, PD can be hereditary. About 10% of patients show either a genetic cause or a change that, despite not causing the disease, augments the risk of developing it. These changes that induce or augment the risk for the disease result from variations in our DNA. DNA is a code that we receive from our parents and that we transmit to future generations, sons and daughters, grandsons and granddaughters and their future descendants. It is this code that determines the structure of our body, the colour of our eyes and of our hair. If this code undergoes a change important enough to cause a disease, we can, for example, produce lower levels of insulin and develop diabetes.

In the case of genetic changes related to PD, our body can have lower levels of certain substances or produce toxic substances that induce disease. Neurons that produce dopamine become altered and disappear, lowering the levels of dopamine in the brain, thereby favouring the appearance of symptoms (such as slower movements, tremor, and rigidity).

Some genetic changes can just induce a higher risk of developing PD, others are sufficient to induce the disease. If the genetic changes only induce a higher risk of developing PD, for example a 5% higher risk, this means that a person instead of having a 1 to 2 % chance of developing PD at 65 years of age (which is the risk of the general population) they would have a 5 to 10% risk of having PD at the age of 65. This risk can be lower or higher depending on the specific genetic change.

If genetic changes cause the disease, those carrying the mutation(s) can develop PD. To date, there are 13 genes (regions in the DNA) that have been identified as causing PD, if altered. These changes/alterations are called mutations. The way the disease starts (sooner or later in life) and the way the disease manifests varies depending on the mutation the patient is carrying. The way the disease appears in the family also varies depending on whether the mutation is recessive or dominant, and if dominant it depends on whether the mutation has a higher or lower penetrance (for example, if just appearing in siblings, or in a father and a son, or in a grandfather and a grandson).

04.IS PARKINSON’S DISEASE HEREDITARY?

Leonor Correia Guedes, *Neurologist*

The most frequent form of genetic PD is caused by the G2019S mutation of the LRRK2 gene. The probability of a patient with PD being carrier of a G2019S mutation can be as low as 1% but this frequency varies from region to region and on whether there is a family history of PD. This frequency is higher in patients from Portugal (where this mutation can be found in around 3.5-5% of patients with PD who do not have any other family member affected, and in ~14% of cases with familial PD) and even higher in patients from the Middle East and North African countries where the G2019S mutation is estimated to be present in more than 30% of PD patients.

PD associated with the presence of the G2019S mutation is very similar to PD with no known genetic cause. It has a similar mean age of onset and disease course and is associated with a lower probability of having cognitive impairment. If a G2019S mutation is identified in a patient, their children will have a 50% probability of inheriting the mutation. Despite this fact, as the mutation has low penetrance, asymptomatic family members carrying the mutation have an estimated probability of developing PD that can be as low as 20% at the age of 80.

The second most frequent known genetic cause of PD is associated with parkin gene (PRKN) mutations. They are associated with a younger age of onset, even before the age of 20 (although this is extremely rare). PD associated with PRKN gene mutations show a more frequent presence of dyskinesia and a more benign disease course, with less frequent cognitive impairment. Other more rare forms of genetic PD can even have an earlier age of onset and can be associated with atypical presentations, lower response to medication, behavioural changes, and more severe cognitive deficits, among others.

The performance of genetic tests in a patient with PD depends on the patient’s desire to know if there are hereditary factors contributing to the illness and on the way the disease manifests in the patient's family. It may also depend on the age of onset and on the clinical symptoms. When deciding whether or not to perform a genetic test it must be taken into account that there is currently no available treatment that prevents or slows down the disease. When performing genetic counselling it is important to explain the pros and cons of genetic testing, that is to say, not only the information provided, but also the possible disadvantageous consequences a positive test has on the patient and his/her family. In this way the patient is able to make a more informed decision.

05.WHAT SHOULD YOU KNOW ABOUT MEDICATIONS FOR THE TREATMENT OF PARKINSON'S DISEASE?

Joaquim Ferreira, *Neurologist*

Fortunately, there are many medications available for the treatment of Parkinson's disease (PD). These medications greatly improve complaints such as tremor and slowness of movement, but are less helpful in treating problems such as gait impairment (e.g., feet stuck to the floor) or speech difficulties, etc. Unfortunately, there are no drugs yet available that cure PD or stop/delay its progression.

The different medications used for the treatment of PD come in different dosage forms: tablets (e.g. levodopa/carbidopa, levodopa/benserazide, ropinirole, pramipexole, piribedil, selegiline, rasagiline, entacapone, opicapone, amantadine), skin patches (rotigotine, rivastigmine), injections into the abdomen (apomorphine), or gels administered through a tube placed directly through the skin into the stomach or bowel (levodopa gel).

Deciding on which treatment is the best needs to be tailored to each individual and depends on the age of the patient, disease stage, lifestyle, treatment goals, and the most troublesome problems (e.g., duration of periods when patients are stiff, slower, and unable to move, and involuntary movements).

Although people with PD may only start treatment with one medication, as the disease progresses it will be necessary to use several medications at the same time. It may also be necessary to take medications at precise moments of the day and at very short intervals (e.g. 3-hour intervals).

Throughout the progression of the disease, doses will have to be adjusted, new drugs will be added and others will be stopped. In the more advanced stages of the disease it is often necessary to lower the dose or stop some of the medications that have been taken for years. There are also medications that, although not specific for PD, can and should be used. Examples include drugs used to treat depression, insomnia (waking up often at night or dreaming a lot), urinary changes (needing to pass urine often at night or having to run to the bathroom), dizziness and falls in blood pressure, forgetfulness, hallucinations (seeing things that are not there), or other behavioural changes. Some medications require very close follow-up. For example, one of the medications recommended to treat hallucinations (clozapine) requires frequent blood collections (initially at weekly intervals).

Like all other medications, drugs for PD can cause unpleasant side effects.

Frequent side effects include complaints of nausea or vomiting after taking a new medication.

In general, these complaints disappear after a few days, but it may be necessary to start increasing the dose of the new medication more slowly or to administer an antinausea drug (e.g. domperidone) for a few days. There are other unpleasant drug side effects that should be reported to the attending physician or neurologist:

- If the patient is very sleepy during the day and falls asleep easily in inappropriate situations (e.g. at the table, driving a car);

- If the patient feels dizzy when getting up;

- If the patient sees strange things that do not exist (e.g. small animals or figures) or engages in unusual behaviours (e.g., compulsive buying or other abnormal behaviours).

Medications with a more complex administration form (abdominal apomorphine injection or infusion of levodopa gel into the bowel) are indicated only for a small group of patients who have long periods in which they are stiff and immobile (OFF periods) or who benefit from being quickly rescued from distressing motor symptoms.

There are many medications that when used to treat problems that are not related to PD can aggravate tremor or other symptoms. Whenever you notice a worsening with the start of a new medication, notify the attending physician.

06.HOW TO TAKE MEDICATION?

Marli Lopo Vitorino, *Nurse*

Parkinson’s disease (PD) is a clinical entity whose treatment includes the frequent taking of several medications. In situations when there are motor fluctuations (alternation between periods when the medication works and the patient feels better and periods when the medication does not work and the patient feels more "blocked"), taking the medication appropriately is even more important. Multiple intakes at the right times, several times a day, and at short intervals (2 to 3 hours) may be needed. When the medication is not taken appropriately, patients may feel its absence or the consequences of its excess.

In this sense, the caregiver can play an important role in the correct administration of medications. It is important to:

1. KNOW THE DIFFERENT MEDICATIONS

It is important to understand the expected effect of the medications and what the possible adverse effects are (e.g. nausea, vomiting, diarrhea). Some adverse effects are particularly important because they have serious consequences, such as the risk of falling asleep at the wheel or compulsive buying. If this happens it is important to tell the doctor so that the medication can be adjusted or changed for another one.

2. ADMINISTER THE MEDICATION CORRECTLY

When preparing medications make sure to re-check all medicines individually paying special attention to their names, dose, and administration times. Be aware that the generic versions of the same drug may have different boxes and appearances.

3. ADMINISTER MEDICATIONS IN RELATION TO MEALS

In people with motor fluctuations it may be advantageous to separate the timing of levodopa (Sinemet® or Madopar® from meals. Protein-rich meals (e.g. meat, fish, hyperprotein supplements) delay the absorption of levodopa, and the onset of effect may occur later or not at all. In these cases, it is recommended to take levodopa at least 30 minutes before or 1 hour after the main meal.

4. RESPECT THE TIME MEDICATIONS ARE PRESCRIBED TO BE TAKEN

At first the medication schedule may be simple, but as the disease progresses it may be necessary to increase the frequency of medicine intake to 6 to 8 times a day, at intervals of 2 to 3 hours.

5. NEVER STOP OR CHANGE MEDICATIONS, EVEN IF THE PATIENT FEELS BETTER

Prescriptions should be respected and neither the patient nor the caregiver should add or omit a medication without consulting their physician. Omitting medications may have the opposite desired effect and cause more discomfort and aggravate symptoms such as tremor or “blocking” sensations.

6. NEVER TAKE A DOUBLE DOSE IF YOU FORGET TO TAKE THE MEDICATION

Levodopa can be taken with a slight delay. However, if the delay is longer than 1 to 2 hours, this dose should not be added to the next one due to the risk of excessive medication.

7. RESPECT THE MEDICATIONS' PREPARATION

Some medications cannot be divided or handled (e.g. capsules or prolonged-release tablets). For some people, the size of pills may be a problem because of the difficulty in swallowing; thus, it is advisable to ingest medication with a soft food (e.g. fruit puree).

8. ASSIST THE TAKING OF MEDICATIONS

In some cases of people with cognitive alterations, memory problems, or behaviour changes, it is essential to provide assistance with taking medicines to avoid the risk of medication not being swallowed.

06.HOW TO TAKE MEDICATION?

Marli Lopo Vitorino, *Nurse*

Given the complexity of medication in PD, there are resources available that can help in preventing overdoses, forgetfulness, and mixing up drugs, such as:

- Disposable box (as a blister) into which all medications for the week can be placed according to the prescribed medication schedule;
- Box with seven compartments according to the days of the week (it is recommended to prepare the medications for the whole week at the same time);
- Daily medication box with four or more compartments, with the medication dose corresponding to the time of intake, identified in the box (recommended for more than four medication intakes per day);
- Plasticised and impermeable charts with the medication schedule that can be put in a visible and easily accessible place (e.g. refrigerator door, wall, office);
- Warning devices to prevent forgetting to take medications (e.g. alarms on the mobile phone, applications that provide reminders when medication should be taken).

A notebook can also be used to write down the patient's complaints when taking medications (e.g. tremor, nausea, vomiting, aggravation of involuntary movements, prolonged blocking sensation), complaints of a new medication, or any questions that may arise, in order to be clarified in consultation with the doctor or nurse.

07.WHEN SHOULD YOU CONSIDER SURGICAL TREATMENT?

Patrícia Pita Lobo, *Neurologist*

In the early stage of Parkinson's disease (PD), patients improve significantly with oral medication. However, with the evolution of the disease and the long-term use of oral levodopa, motor complications may arise. Motor complications develop slowly during disease progression and are characterized by two types of symptoms / complaints: OFF periods and involuntary movements.

OFF periods correspond to the periods of the day when PD symptoms reappear (tremor, slowness, stiffness, walking difficulties, and freezing). These periods can be predictable or unpredictable throughout the day, despite regular medication intake.

Involuntary movements, called dyskinesias, are movements independent of patient control, and can develop in any part of the body (head, trunk and limbs). These movements are associated with the intake of levodopa throughout the day.

With the progression of the disease, both OFF periods and involuntary movements may become more frequent during the day, unpredictable and quite intense, causing patient discomfort and disability when performing activities of daily living.

Which patients are candidates for Parkinson's disease surgery?

Patients with PD who have OFF periods and troublesome involuntary movements (dyskinesias) that limit their activities of daily living and that do not improve with the best oral treatment.

What are the symptoms that improve with Parkinson's disease surgery?

The symptoms that improve with PD surgery are: slowness of movement, limb stiffness, and tremor. There is also a significant reduction or even remission of OFF periods and involuntary movements.

What are the conditions that can make a patient not a good candidate for surgery?

- Gait problems that do not improve with oral medication;

07.WHEN SHOULD YOU CONSIDER SURGICAL TREATMENT?

Patrícia Pita Lobo, *Neurologist*

- Frequent falls and significant imbalance that does not improve with medication;

- Memory problems;

- Severe depression or behavioural changes (e.g. hallucinations);

- Other diseases or metallic material in the body that contra indicate Magnetic Resonance Imaging (MRI).

Who refers patients to the specialized surgical team?

The neurologist who routinely follows the patient may refer him/her to the surgery centres.

Where is Parkinson's disease surgery performed?

In hospitals that have teams dedicated to PD surgery.

How does surgery work?

The most frequently performed PD surgery is deep brain stimulation surgery. This surgery involves the placement of brain electrodes that are attached to a neurostimulator (a type of pacemaker with a battery) that is placed under the skin at the level of the patient's chest.

What are the risks of surgery?

In centres with more experience, adverse events of surgery occur in 1 to 2 patients out of 100 who undergo the procedure and include:

- Infections of the materials implanted during surgery;

- Cerebral hematomas and strokes;

- Severe involuntary movements;

- Worsening of speech (dysarthria), walking and balance problems;

- Worsening of memory problems, depression and anxiety;

- Non-improvement of PD symptoms.

07.WHEN SHOULD YOU CONSIDER SURGICAL TREATMENT?

Patrícia Pita Lobo, *Neurologist*

AFTER SURGERY

The patient must maintain regular follow-ups in an outpatient clinic. In the clinical visits the medication and stimulation parameters are adjusted to improve the PD symptoms.

08.WHEN SHOULD YOU TALK TO THE DOCTOR?

Ana Castro Caldas, *Neurologist*

The symptoms and related problems of Parkinson's disease (PD) vary throughout the progression of the disease and can even do so from day to day. It is a disease in which the possibility of an easy contact with health professionals is very important. A trusting relationship with the doctor and regular consultations are an important part of treatment. Although the problems encountered by the patient may seem embarrassing and uncomfortable, they can often be easily resolved by healthcare professionals.

You should therefore contact your doctor or someone on the healthcare team whenever the person you are caring for:

- Has questions about the illness, including what causes it, questions about the available treatment options or problems related to medications;

- Has a worsening of symptoms after medication changes, such as aggravation of slowness or tremor, or increasing involuntary movements (dyskinesias);

- Has difficulty in walking and suffers falls;

- Has cognitive problems (difficulty remembering events, paying attention, planning or following a conversation or thinking);

- Feels pain in their feet when waking up;

08.WHEN SHOULD YOU TALK TO THE DOCTOR?

Ana Castro Caldas, *Neurologist*

- Has sleep problems;
- Often has the need to go to the bathroom at night;
- Has visual hallucinations (hallucinations occur when a person, while awake, sees or hears things that are not there/happening);
- Has false beliefs not based in reality (for example, the idea that there is another person living at home, or that someone wants to steal from him/her, or jealousy);
- Has new interests or hobbies that take up too much of their day;
- Has excessive behaviours related to shopping, food, and/or sexual activity;
- Becomes aggressive or suspicious;
- Feels anxious, sad, or lacks motivation in performing daily activities or is unwilling to continue living;
- Has violent nightmares that are associated with aggressive behaviours as if they were acting out their dreams (e.g. screaming, or kicking or kicking while asleep);
- Has episodes of fainting or near fainting;
- Shows signs of swollen or purple discoloration in the form of a net on the legs.

All doubts must be mentioned to a healthcare professional, even if you fear that they may be unreasonable. Time with the doctor may be limited, so it is important that the patient and/or the caregiver prepare for the appointment. The patient/caregiver should prepare a list of all medications, a list of possible problems related to medications, a list of complaints or more uncomfortable problems issues, as well as tests performed (e.g. blood test results, MRI, etc.).

09.WHAT TO SAY AND ASK THE NEUROLOGIST DURING AN APPOINTMENT?

Joaquim Ferreira and Marisa Brum, *Neurologists*

In the follow-up of the person with Parkinson's disease (PD), the information shared at the time of the consultation is extremely important. Many of the decisions to be made depend on what is reported to the doctor, not just on what is observed during the appointment. This information concerns what happens during the day and can be transmitted by the patients themselves, by family members, or caregivers. To facilitate and improve the collection of this information by the physician or other health professionals (e.g. nurse, physiotherapist, etc.), one possible solution is for the patient or caregiver to take written notes to the clinical office to ensure that everything they consider important is transmitted to the doctor. This strategy also ensures that the information transmitted is as accurate as possible.

Below are some examples of information that may be shared with the physician, as well as sample questions that could be asked. We separate the information that can be communicated in a first consultation, and in subsequent visits, where the doctor will have more knowledge about the individual with PD.

Examples of data to be transmitted in a first appointment:

- What is the main reason for making the appointment?

- When did the complaints that led the patient to make the appointment begin?

- What was the first complaint noticed by the patient or a family member?

- What medications are being taken now, at the time of the consultation, and what were the medications being taken when the complaints started, or even before the complaints started (we suggest that a detailed listing or box-cutting/photo of the medication showing the name and dosage should be brought to the consultation)?

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- Which examinations have already been undertaken to investigate the complaints (we suggest taking the examinations and reports to the consultation)?

- Take discharge notes from previous hospital admissions.

- List of all relevant medical problems or illnesses the patient has had throughout their life (surgeries, hospitalizations, allergies, serious diseases, etc.).

- List of the most uncomfortable current complaints (e.g. tremor, involuntary movements, difficulty sleeping, constipation, etc.).

- At what time of the day are complaints most troublesome and at what time of the day does the patient feel better?

- Which medications have improved the complaints and which medications may have aggravated the symptoms?

- What do relatives, who are not present at the consultation, say about the patient's complaints?

- Are there are other family members with similar complaints or illnesses?

Examples of questions to ask the doctor at a first consultation:

- What is the name of the disease you think the patient has?

- What is the purpose of the requested tests?

- Is the proposed diagnosis considered definitive or do the requested tests still have the purpose of clarifying it?

- How do you think the disease will develop and what should the patient and their family expect to happen in the future?

- What is the risk of my children having the same disease?

- What is the purpose of the prescribed drugs and what benefits/adverse effects should be expected?

- What unexpected things may happen and what should be done in such circumstances?

- In addition to the prescribed medications is there something else that should be done (e.g. physiotherapy, speech therapy, exercise, etc.)?

- Can the patient continue to drive?

Examples of information to tell the doctor at a follow-up visit:

- The most relevant thing that has happened since the previous consultation (e.g. a new illness, hospitalization, infection, surgery, fall, etc.).

- Any change in the medication compared to the previous visit.

- The most troublesome or uncomfortable problems the patient is experiencing.

- During which period of the day the patient is the most comfortable and when the most troublesome complaints happen.

- If the patient sleeps well but their spouse complains that they talk or move a lot at night.

- The patient's mood, whether they are sad, anxious or discouraged.

- If something strange happened during this period (e.g. seeing things that do not exist, excessive tendency to buy things, or spend too much money, etc.).

Examples of questions to ask the doctor at a follow-up visit:

- Has there been any change in the recommendations that had been given in previous consultations?

- Is there any new treatment that should be started?

- Which other disease-related problems may arise over time?

OTHER RECOMMENDATIONS

- Although the consultation is a moment of privacy between the patient and the doctor, the presence of a companion, family member, or caregiver is often advantageous because there is information about important aspects that they can answer better than the patient him/herself (e.g. changes in mood or behaviour).

- Nowadays, one way to show the doctor what is happening at home is to film these events with a mobile phone; in this way it is possible to share with the doctor which movements or other problems occur and are difficult to explain in words.

10. WHEN TO TAKE THE PERSON WITH PARKINSON’S DISEASE TO THE HOSPITAL?

Marisa Brum, *Neurologist*

The experience of going to a hospital, whether planned or unplanned, causes discomfort to everyone. For people with Parkinson’s disease (PD), going to the Emergency Department (ED) of a hospital should not be taken lightly. PD progresses slowly and can be effectively managed through regular visits to a neurologist with experience in movement disorders. For this reason, people with PD are unlikely to be admitted to hospital because of the disease itself, except for the surgical intervention known as deep brain stimulation. Health problems not directly related to the disease are, therefore, the main reason why people with PD need hospital care.

MAIN REASONS TO GO TO THE HOSPITAL	COMMON POTENTIALLY ASSOCIATED ISSUES
Falls	**Bone fractures**
Shortness of breath	**Pneumonia**
Urinary complains	**Urinary infection**

Recent studies show that when people with PD are admitted to hospital - usually for reasons unrelated to the disease, such as a scheduled surgery - they have longer stays and more often require prolonged rehabilitation. In addition, going to a hospital may lead to an increased risk of infection. The hospital environment is challenging. Anxiety related to being in an unfamiliar place can aggravate the symptoms of the disease. In addition, the ED team may not be familiar with some of the symptoms of PD. ED physicians are focused primarily on treating the condition that brought the patient to the ED, which (as mentioned above) is probably not directly related to PD itself. The admission to the hospital may cause changes in the timing of medication intake, discontinuation of some medications, and changes in sleep pattern.

If you take the person with PD to the hospital ensure that you bring their medications with you, as they may not be available in the hospital pharmacy, and the medication schedule - so that the medication can be given at the usual time. If the patient has

10.WHEN TO TAKE THE PERSON WITH PARKINSON'S DISEASE TO THE HOSPITAL?

Marisa Brum, *Neurologist*

difficulty walking and needs support (walking sticks, canes), it will also be useful to take the home walking aids.

People with PD should go to the ED when they feel they may have an infection that is worsening their neurological state or following falls with suspected fractures. Before going to hospital due to worsening of known PD fluctuations (e.g. more OFF periods, memory and concentration changes or hallucinations), they should first contact the neurologist who knows the best therapeutic strategy for the problem.

REMEMBER

BEFORE TAKING THE PERSON WITH PD TO THE HOSPITAL CONSIDER WHETHER

These are new symptoms which raise doubts about the severity

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These are health problems that may be serious and which are not directly related to the known symptoms/fluctuations of PD

PROBLEMS THAT ARE RECURRENT, THAT THE TREATING NEUROLOGIST IS AWARE OF, AND ARE NOT INTOLERABLE, ARE NOT A REASON FOR WHICH THE PERSON WITH PD SHOULD BE TAKEN TO THE HOSPITAL.

11.HOW TO DEAL WITH LIGHT-HEADEDNESS AND SUDDEN FALLS IN BLOOD PRESSURE?

Rita Simões, *Neurologist*

What is a sudden fall in blood pressure?

Blood pressure is represented by a pair of numbers: the top number is the systolic blood pressure and the bottom the diastolic blood pressure. Sudden falls in blood pressure are happen when it decreases abruptly to a very low level. Normal systolic blood pressure is around 100-140 mmHg and normal diastolic blood pressure is 60-80 mmHg.

Blood pressure varies during the day. It is expected to be lower during sleep and after meals, and higher when one is in pain or anxious. This variability is normal and is regulated by systemic mechanisms. If blood pressure is very low, blood flow to the brain may be compromised and one can feel lightheaded or even faint.

Can sudden blood pressure drops occur in Parkinson's disease (PD)?

Yes. In PD, blood pressure regulatory mechanisms may be compromised and blood pressure can suddenly drop. This is more common in those who have had the disease for several years.

When do sudden blood pressure drops occur?

Sudden blood pressure drops are frequent in the following situations:

- After standing for a while in the same position;

- After meals, especially "heavy" meals or after drinking an alcoholic beverage;

- In heated rooms and hot weather (they are more frequent in the Summer);

- After physical exertion (exercise, physiotherapy).

In all these situations there is a normal decrease in blood pressure. However, in PD, regulatory mechanisms may not be able to stop the fall in blood pressure and symptoms occur.

11.HOW TO DEAL WITH LIGHT-HEADEDNESS AND SUDDEN FALLS IN BLOOD PRESSURE?

Rita Simões, *Neurologist*

What are the symptoms of sudden drops in blood pressure?

Light-headedness or dizziness are the most frequent symptoms. In more severe situations the person becomes pale, sweaty and can even fall or faint. Other symptoms include sleepiness, tiredness, generalized weakness, lack of energy, blurred vision, abnormal ear sensations, headache, chest pain, and shoulder pain. Blood pressure should be checked if, after lunch, the person with PD becomes tired, apathetic, or sleepy or needs to take a nap. Falls in blood pressure can also occur without symptoms.

What to do when blood pressure falls?

In case of a sudden fall in blood pressure the person should immediately sit or lie down and stay in that position for several minutes. Raising the legs could be of some help. These manoeuvres help blood flow to the brain, revert symptoms, and prevent fainting.

How do you prevent falls in blood pressure?

There are simple measures that help to prevent falls in blood pressure and avoid symptoms. The person with PD should:

- Avoid standing still. When standing for a while, some leg exercises should be carried out: walking, moving up and down, contracting leg muscles, crossing legs, moving toes, forward flexion;

- Avoid heated rooms, hot baths, going out in hot weather;

- Prefer more frequent and lighter meals;

- Avoid salt restriction;

- Avoid alcoholic beverages;

- Drink coffee after meals;

- Ensure adequate fluid intake (e.g. drink 2.5 litres of water a day if possible). Pay attention to hydration before exercising (e.g. drink a small bottle of water before physiotherapy).

The doctor should be informed of symptoms and when they occur, and blood pressure measurements should be noted. Compression tights may be advised.

12.HOW TO DEAL WITH MOOD SWINGS?

João Lourenço, *Neurologist*

Mood fluctuations are part of our natural response to emotions and events that occur in our daily lives. These mood fluctuations can, in some diseases, become more frequent or prolonged than normal and even be decontextualized from the situation.

In Parkinson's disease (PD), mood disorders can occur in various forms, such as: depressive episodes, persistent depressive disorder, or maniac/hypomaniac disorder.

These mood disorders can be related to PD itself or may manifest as a reaction to the incapacity caused by the disease. Mood swings can significantly reduce the quality of life of patients with PD because they impair the capacity to perform activities of daily living.

DEPRESSIVE SYMPTOMS:

These are the most frequent mood swings in PD and are present in approximately 50% of patients. The most important red flags that one should be on alert for are: frequent feelings of sadness and anguish, feeling fatigued or lacking energy and motivation, difficulty concentrating and reasoning, decreased interest or pleasure in daily activities, inappropriate feelings of guilt or worthlessness, increased or decreased weight and/or appetite, recurrent thoughts about death and suicide, sleep disturbances, such as insomnia or sleepiness during the day, and feelings of indifference or lack of emotions.

Depressive symptoms can, in some circumstances, only happen in periods of more motor impairment (OFF periods), or be present in a more persistent way.

In the case depressive symptoms occur only during OFF periods, the lack of dopamine may be the cause, in which case an adjustment of the PD medication may be beneficial.

For patients and caregivers, the first step is to recognize these symptoms and communicate them to the attending physician. These symptoms should be considered as important as the motor symptoms of PD.

12.HOW TO DEAL WITH MOOD SWINGS?

João Lourenço, *Neurologist*

MANIAC/HYPOMANIAC SYMPTOMS:

These are symptoms of euphoria accompanied by increased self-esteem, self-confidence, irritability, and grandiose ideas, which can lead to imprudent behaviours. These symptoms occur less frequently than depressive ones, and are usually related to the PD medication or to deep brain stimulation. When noticed, these symptoms should be communicated to the attending physician as soon as possible.

In face of these mood swings, caregivers should act comprehensively and patiently. Appropriate treatment of mood disorders in PD can have a significant positive impact on the quality of life of PD patients and their caregivers.

13.HOW TO DEAL WITH BEHAVIOURAL MANIFESTATIONS OF PARKINSON'S DISEASE?

Inês Chendo, *Psychiatrist*

Although Parkinson's disease (PD) is primarily a movement disorder, non-motor manifestations such as behavioural or psychiatric symptoms are also very important. Psychiatric alterations are common affecting around 60% of patients. These alterations are the result of a combination of factors:

- Brain changes secondary to PD itself;

- Psychological or emotional factors;

- Dopamine-replacement therapy (for the treatment of PD-associated effects).

In people with PD, both the severity and frequency of psychiatric symptoms increase as the disease progresses. These symptoms can even become dominant in the later stages of the disease, and negatively impact both PD patients and their caregivers.

Some psychiatric symptoms, such as psychotic features (e.g. hearing voices or noises, seeing things that are not real, believing you are being misled or the victim of foul play) are frequently associated with the need for institutionalization (for example, in nursing homes) and more severe disease outcomes.

The most frequent neuropsychiatric manifestations of PD are:

1. AFFECTIVE DISORDERS

a. These include depression (with varying degrees of severity) and diseases belonging to the bipolar disease family;
b. Depression is one of the most common psychiatric diagnoses in PD, affecting around half of patients.

2. ANXIETY DISORDERS

a. These include generalized anxiety states, panic attacks, and phobias;

b. Anxiety disorders occur in around 40% of people with PD.

3. APATHY

Usually characterized by a decrease in motivation and interest in daily activities, a lack of initiative (e.g. staying inactive for long periods, giving up going out for a coffee or to meet friends, or losing interest in previously enjoyed or usual activities).

4. PSYCHOSIS

May include:

a. Low severity alterations, such as illusions (e.g. mistaking a hanging jacket for a person), or having a feeling someone is present or walking by;

b. More severe alterations, such as hallucinations (usually visual hallucinations, like seeing animals or human figures) and delusional ideas (e.g. believing someone wants to mislead, cheat or be dishonest with you).

5. MILD COGNITIVE IMPAIRMENT AND DEMENTIA

6. IMPULSIVE AND COMPULSIVE BEHAVIOURS

These may include:

a. Serotonin dysregulation syndrome:

i. May happen if patients take more medication than necessary to control motor symptoms.

b. *Punding:*

i. Having a fascination for specific, repetitive activities (e.g. spending many hours manipulating and organizing objects with no recognizable purpose, like documents or clothes, or collecting items).

c. Impulse control disorders:

i. Pathological gambling - having difficulties avoiding the impulse of gambling, and spending a lot of money on the lottery, in casinos, or on online gambling;

ii. Hypersexuality - having an increase in sexual desire and drive, often accompanied by frequent and inappropriate attempts to engage in sexual activities;

iii. Compulsive shopping - spending a lot of money on unnecessary items;

iv. Binge eating - having an inappropriate and exaggerated increase in appetite and drive to ingest food.

The psychiatric manifestations of PD often go underdiagnosed and, for this reason, may be inadequately treated.

It is important that people with PD and their caregivers are aware that these psychiatric alterations are a possibility.

The treating physician should frequently ask about these symptoms during the course of the disease. This will enable them to be identified early on and, if necessary, the person with PD can be referred to a psychiatrist who will characterize the symptoms in detail, ask specific questions and objectively observe signs that are fundamental for an accurate diagnosis. The timely identification and treatment of the psychiatric symptoms of PD reduces their associated disability and improves the quality of life of both the person with PD and their caregiver.

Treatment of the psychiatric manifestations of PD

The treatment of these alterations is often complicated, mainly because medication used to treat the psychiatric symptoms of PD can sometimes worsen the motor symptoms of the disease. In order to treat psychiatric manifestations of PD, it may be required to:

- Adjust the medication used to treat PD;

- Engage in a structured, frequent psychological support program;

- Use medication that is specific to these symptoms (such as antidepressants, anxiolytics, and antipsychotics);

- Teach the PD patient and caregiver how to deal with behavioural symptoms.

14.HOW TO DEAL WITH MEMORY LOSS?

Vanda Freitas Castro, *Clinical Neuropsychologist*

What is memory loss?

Memory is the cognitive ability that allows an individual to store, retain, and recover information or experiences. It is important for daily activities and survival. It is what makes us human and gives meaning to who we are and what we do.

Forgetting is a common phenomenon experienced by everyone and, as we grow older, tends to be more and more present. In some neurological diseases, like Parkinson's disease (PD), this "forgetfulness" can be a cause of concern for patients and their caregivers and can be taken as a sign of cognitive decline, which can reduce independence and quality of life.

What kind of memory loss?

A person with PD may develop difficulties with short-term memory, also known as "working memory" (e.g. difficulty repeating a phone number), as well as with long-term memory (e.g. trouble organizing and processing information, difficulties learning a new task). Procedural memory may also be affected (e.g. forgetting how to do a certain task).

Is it possible to prevent memory loss?

Cognitive changes are considered a non-motor manifestation of PD. It is not possible, however, to prevent them. With advances in general health care, life expectancy tends to rise, which in turn can lead to an increase in the number of people with cognitive changes.

The course of these changes in PD, namely memory loss, tends to be slow and can be managed through strategies that help with daily activities.

What to do about memory loss?

- Be aware of memory complaints (they can be a sign of memory decline);

- Talk about forgetfulness to the neurologist;

- Undertake a memory evaluation in order to clarify and quantify cognitive/psychological difficulties;

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Vanda Freitas Castro, *Clinical Neuropsychologist*

- Enrol in a cognitive training program with a psychologist experienced in cognition, in order to compensate deficits and obtain adaptive strategies;

- Be aware of depressive symptoms (these can aggravate memory deficits).

What are the strategies for dealing with memory loss?

The caregiver of a person with PD can implement small strategies that help with daily tasks:

- Use of memory auxiliaries (i.e. mobile phone, message board, agenda);

- Reinforce an easy and quick way to access important information (i.e. medication schedule, doctor appointments, calendar);

- Register new information in a notebook;

- Encourage tasks that stimulate attention (i.e. crosswords, letter soup, etc.);

- Adapt the patient's home, and avoid unnecessary changes;

- Establish routines, create a familiar, simple and safe environment;

- Simplify, give simple plain instructions and allow only one task to be done at a time;

- Maintain physical and social activities.

Try to maintain a positive and calm attitude, do not take patient's forgetfulness personally, because the patient cannot control it. Avoid frustration by assisting and helping the patient to remember.

15.HOW TO DEAL WITH URINARY PROBLEMS?

Márcia Duarte, *Nurse*

Urinary problems are frequent in Parkinson's disease (PD) and can greatly affect quality of life. In PD there is a change in the transmission of information from the brain to the bladder, causing an interruption in the messages sent to store or control the release of urine. The most common problem is not being able to hold urine in the bladder, resulting in the following symptoms:

- Involuntary loss of urine;
- Need to run to the bathroom;
- The need to urinate often during the night.

Another common problem is the difficulty in eliminating urine. In this case the following complaints may arise:

- Urinating in small quantities;
- Involuntarily loss of small amounts of urine;
- A feeling that the bladder has not been completely emptied.

The attending physician, a neurologist, or a urologist can prescribe medication to help control these symptoms.

Moreover, there are specific exercises that can be useful to help strengthen the pelvic muscles (muscles that support the bladder). A nurse or a physiotherapist can advise some on strategies, according to the complaints that predominate.

Bladder training can be used to help the bladder to learn how to retain a larger amount of urine and increase the interval between trips to the bathroom.

Surgery may be indicated in some particular situations.

Other strategies that can help control symptoms (mentioned above) are related to lifestyle changes, such as:

- Avoiding foods and beverages that can irritate the bladder (e.g. tea, coffee, alcoholic beverages, Coca-Cola® and other fizzy drinks, tomatoes, chocolate, and spicy foods);
- Maintaining a healthy weight;
- Drinking an appropriate amount of liquid (6 to 8 glasses a day); the ideal is to drink a good amount during the day and decrease the intake later in the evening, especially at night 1 hour before bedtime;
- Stop smoking;
- Maintaining regular bowel habits.

There are also some strategies that can help deal with urinary disorders:

- Using a footrest to elevate feet off the ground, if the toilet is high (provides greater comfort);
- Using a toilet seat lift, if it is too low;
- Placing auxiliary handles/brackets on the floor or wall for facilitating going to the toilet;
- Wearing clothes that are easy to take off (e.g. Velcro and elastic waists are faster and easier than buttons or zippers);
- Use products for incontinence such as:
    - Incontinence pads (for both men and women) with various sizes and absorption capacities;
    - Washable pants (suitable for men and women) similar to normal underwear (in terms of appearance and comfort) that provide the added security of an incontinence pad;
    - Waterproof mattress protectors for the accidental loss of urine or incontinence;
    - Underwear with velcro attachments and elastic pants to facilitate going to the toilet either by oneself or with help from a caregiver;

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Márcia Duarte, *Nurse*

- Urinals to avoid trips to the bathroom during the night.

It is also important to be aware of the following points and to contact the doctor should any of these problems develop:

- Inability or difficulty emptying the bladder (even when it seems full);
- Uncontrolled loss of urine in any situation;
- Need to urinate more often than usual;
- Urgent need to urinate;
- Pain when urinating;
- Blood in the urine.

16.HOW TO DEAL WITH CONSTIPATION?

Marta Pires, *Nurse*

Parkinson's disease (PD), in addition to causing motor symptoms, presents non-motor symptoms that can significantly affect the patient's quality of life. These non-motor symptoms can occur at any stage of the disease, including before the onset of motor symptoms. Constipation is one such symptom.

What is constipation?

Constipation is characterized by a change in the intestinal elimination pattern, that is, a change in the frequency of bowel movements or consistency of stools. Constipation is subjective as there is no correct number of bowel movements and each person knows what is normal for them. There are, however, some signs that may help identify a problem:

- A feeling of not being able to completely pass the stools through the rectum;

- Hard stools, with difficulty and pain or straining when having a bowel movement;

- Bowel leakage can also be a sign of constipation (when stools accumulate in the final portion of the intestine, they can become too hard and block the rectum, allowing only liquid stools and mucus to pass through).

Is constipation a frequent problem in PD?

Constipation can affect anyone, but people with PD are more likely than the general population to suffer from the condition. In PD, chewing and swallowing can be affected to the point that it becomes difficult to eat a high-fibre diet and drink the right amount of water, therefore worsening bowel function. Medication may also contribute to the occurrence of constipation. If, on the one hand, some medication can cause constipation, on the other hand, constipation itself can influence how medication is absorbed, altering its effect.

What can you do?

Once the problem is identified, it is important to inform the physician so that he/she can evaluate the need to review the treatment or prescribe laxatives. In addition to the doctor, other members of the healthcare team can help find strategies to prevent

16.HOW TO DEAL WITH CONSTIPATION?

Marta Pires, *Nurse*

or combat constipation through non-pharmacological measures. At the same time it is possible to adopt some diet-related strategies as well as exercise and daily routines such as the ones outlined below.

DIET

A diet high in fibre and fluid increases bowel consistency and efficiency. It is therefore important to:

- Eat foods with a laxative effect (e.g.: plums, honey, oranges, mandarins, mangoes, avocados, corn);

- Eat foods rich in dietary fibre (e.g.: fresh fruits, vegetables);

- Substitute white bread for whole-grain bread;

- Increase water intake to 1.5L per day. This includes water, tea and natural juices;

- Avoid consumption of carbonated drinks (may cause swelling) and alcoholic beverages (may cause dehydration);

- Avoid consumption of food with a constipating effect (e.g.: white rice, pasta, flour, bananas, potatoes, carrots, etc).

EXERCISE

Physical exercise helps relieve or prevent bowel problems by stimulating intestinal muscles and strengthening the pelvic muscles (used in the elimination of stools). Even if exercise becomes more difficult due to limitations caused by PD, it is important to avoid a sedentary lifestyle.

You may want to consult with the physical therapist about specific exercises, but also favour simple activities such as:

- Hiking;

- Housework;

- Frequent changes in position.

16.HOW TO DEAL WITH CONSTIPATION?

Marta Pires, *Nurse*

ROUTINES

The creation of routines is key in regulating intestinal transit, since it is possible to "train" the intestine. In this sense, you can implement strategies such as:

- Establishing a time to go to the toilet (ideally during the ON period, when the patient is not blocked);
- Do not delay going to the toilet when the urge arises;
- Ensure feet are supported on the floor (or on a non-slip rug/pad) to correct posture when on the toilet;
- Do not stay on the toilet for long periods; if you can not have a bowel movement you should try again later;
- Drink a glass of hot water on an empty stomach.

In cases of significant weight loss, rectal bleeding, severe abdominal pain, nausea, or constipation that lasts longer than five days, you should tell your doctor or go to a healthcare facility. It is important that constipation does not cause unnecessary stress to either the person with PD or their caregivers.

17.HOW TO DEAL WITH SLEEP COMPLAINTS?

Rita Peralta, *Neurologist*

Sleep complaints are very common in people with Parkinson's disease (PD). The most common of which are abnormal behaviours during sleep, insomnia, and excessive daytime somnolence.

REM sleep behaviour disorder

A disease called REM sleep behaviour disorder usually causes abnormal behaviours during sleep. These symptoms may begin years before the more classic motor symptoms of PD. While we sleep and dream our muscles are paralysed and we cannot move. In this disorder, however, the muscles remain active throughout sleep and people act according to what they are dreaming. The movements are varied and range from speaking and small facial or limb spasms to vigorous screaming and dramatic movements where the action of the dream seems to be performed (for instance, grabbing objects, punching, or kicking). Dream content is frequently aggressive including situations where the dreamer is fighting or running from dangerous situations, leading to aggressive behaviours. This may lead to the patient hurting him/herself or his/her partner. This disorder is easily treated with medication (mostly clonazepam or melatonin). It is very important to mention these symptoms to the doctor. As many people with PD are not aware of these problems due to the fact that they are sleeping while they happen, bed partners and caregivers should talk about this in the clinical visit.

Excessive daytime sleepiness and insomnia

Excessive daytime sleepiness and insomnia in PD may have many different causes. The disease itself affects areas of the brain that are close to the areas that control sleep and wakefulness and synchronize them to diurnal and nocturnal periods. In some people with PD these mechanisms may be less effective, leading to sleep problems.

Besides this reason, however, many other factors may be responsible for sleepiness or insomnia:

- Side-effects of medications;

- Anxiety and depression;

- Other PD symptoms that occur during the night – difficulty moving in bed, abnormal and, sometimes painful, limb contractions (dystonia), pain, sweating, hallucinations, increased necessity to urinate;

- Restless legs syndrome – this disorder, which occurs more frequently in people with PD, leads to an irresistible urge to move the legs, frequently accompanied by unpleasant feelings or even pain, and usually occurs in the evening or at night;

- Lifestyle – in more advanced PD stages people have important motor limitations and become mostly sedentary. Most of the day is spent at home, with little physical activity and exposure to sunlight. Our brain is very sensitive to sunlight and this is one of the most important stimuli for us to synchronize sleep with night-time and wakefulness with daytime. Our brain needs to receive lots of light during the daytime and little light during the night hours;

- Finally, insomnia and sleepiness are also inter-related: sleeping less well during the night leads to daytime somnolence. Similarly, napping during the day, frequent in people with sleepiness, leads to insomnia.

Treatment of sleep disorders in PD is complex because of all these possible causes of sleep disruption. However, it is always possible to decrease symptoms and improve quality of life. When evaluating sleep problems it is frequently necessary to perform a sleep exam called a polysomnography. This exam basically records what happens to the body during sleep (brain and muscle activity, heart rate, respiration), frequently with video monitoring. With this exam it is possible to diagnose REM sleep behaviour disorder, as well as other sleep disorders such as obstructive sleep apnea. Sleep apnea is a very common disorder and may contribute to all sleep complaints in PD. Treatment of sleep apnea may alleviate insomnia, excessive daytime sleepiness and even abnormal behaviours during sleep. There are also other pharmacological and psychological treatments that are very useful for sleep problems.

The best way to deal with sleep problems in PD is to mention them to your doctor, preferably with the help of your caregiver or bed partner.

These are the symptoms that should be reported to the doctor:

- Difficulty falling asleep;

- Waking up very frequently during the night;

- Waking up very early in the morning;

- Feeling sleepy during the day. Even when performing tedious or non-active tasks like reading or watching TV it is not normal to fall asleep or doze off;

- Waking up tired and feeling un-refreshed;

17.HOW TO DEAL WITH SLEEP COMPLAINTS?

Rita Peralta, *Neurologist*

- Having “sleep attacks” – this is a more extreme manifestation of sleepiness in which sudden sleep occurs, even in active situations, like talking or eating, without previously feeling sleepy. It can lead to serious accidents;

- Abnormal sleep behaviours.

Before consulting a doctor, there are behavioural measures that should be started:

- Avoid a sedentary lifestyle, maintaining physical activity during the day, adequate to your physical condition. Refrain from vigorous physical activity close to night-time;

- Avoid heavy meals, especially at night-time;

- Reduce intake of liquids at dinner and in the evening to reduce night-time urine production (but remember to drink enough liquids throughout the day);

- Avoid daytime naps. However, if excessive sleepiness is a serious problem, a small nap of 30-60 minutes after lunch may improve your alertness;

- Avoid staying in bed more hours than the ones you need to sleep - there is no established number of hours to sleep, it is an individual trait, although it is usually between 6-8h/night. Your perfect number of sleeping hours would be the one that leads to feeling refreshed after waking up and without somnolence during the day;

- Establish a regular sleep schedule. Ensure this sleep schedule is in accordance with your preferences in terms of sleeping time and needs (some people are night owls – prefer to sleep late – and other are early birds – prefer to sleep early);

- Ensure you have adequate exposure to sunlight during the day;

- Ensure your sleeping environment is comfortable, adequately dark, warm, and quiet;

- Stimulants like caffeine or tea should only be taken in the morning;

- Alcohol should not be consumed at dinner/night-time;

- If you have abnormal behaviours during sleep, protect yourself by adapting your environment by removing all objects that may cause injury, for instance glass objects from the night stand; cushion your bed; use side protections and preferably use a bed closer to the ground. **Avoid using restraints on your limbs as they may lead to lesions if you move them violently.**

18.HOW SHOULD I TAKE CARE OF MY VOICE?

Rita Cardoso, *Speech and Language Therapist*

How can Parkinson’s disease (PD) affect the voice?

The different components of speech production such as inspiration, vocal folds vibration, and articulation, are supported by muscles that may become rigid and present tremor due to Parkinson’s disease (PD). Among the different components of speech production, voice is the most affected in DP, however, other components such as articulation, respiration, and resonance may also be compromised.

Which are the most frequent speech problems/features in PD?

The most frequent features of speech problems in PD include reduced volume, decreased voice expressivity, a hoarser or softer voice, imprecise word articulation, changes in the speed of speech (talking slower or faster than usual), episodes of “freezing of speech", syllable repetition, and other stuttering-like episodes. It is also common that people with PD feel that their voice fails in the middle of a conversation or they can feel tired during or after participating in long conversations.

Reduced volume of the voice has the singularity of being frequently associated with a lack of self-perception regarding this particular change. For example, it is common that the person with PD explains the frequent repetition requests from family and friends as a consequence of their lack of hearing ability or environmental noise, not recognizing that their own quiet voice is the main reason others have difficulties understanding him/her.

What can I do to preserve my voice?

Use it! People with PD should seek to maintain an active social life as a way of guaranteeing opportunities for using their voice. Joining a choir is also a way to maintain these opportunities; however, people with PD may need a longer vocal warm up with a slower progression of pitch changes than the rest of the group.

What should I do if my voice has already changed?

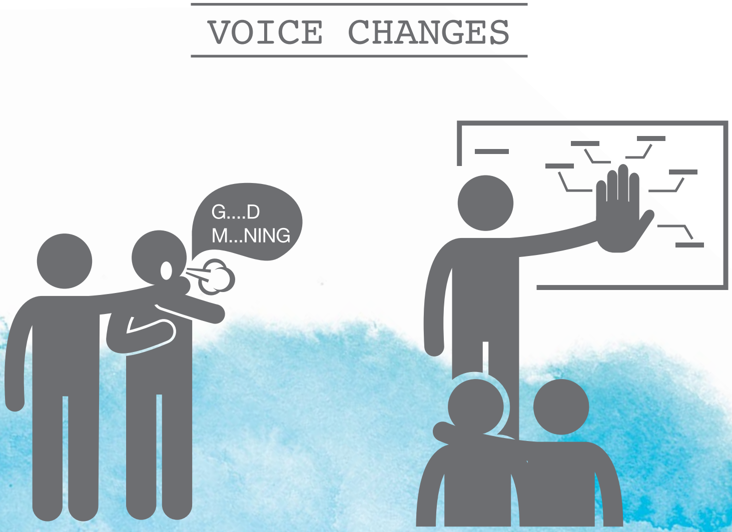
For some patients or for patients in advanced stages of the disease, maintaining an active social life may not be enough to preserve their voice. Any change in speech ability must be discussed with the neurologist or with a speech and language therapist.

18.HOW SHOULD I TAKE CARE OF MY VOICE?

Rita Cardoso, *Speech and Language Therapist*

There are effective techniques and exercises developed to help manage the speech problems associated with PD. These health professionals will provide advice and establish the most adequate approach to treating these symptoms.

What kind of strategies can improve communication with someone with PD?
Ask the person to talk LOUDER! Do not ask them to talk loud, as this will make them uncomfortable. Talking louder will help the person with PD to do deeper and more effective inspiration, which will contribute to a louder voice and better word/speech articulation. This way, not only will there be a change in the voice's volume but also a global improvement in the different speech components. Besides this, reducing environmental noise (e.g. closing windows or switching off the television) or promoting face-to-face communication can be helpful).



19.FOODS TO EAT AND AVOID?

Diana Miranda and Joana Breda, *Nutritionists*

The promotion of an adequate nutritional status in patients with Parkinson's disease (PD) should be a major goal through all stages of the disease.

Although there is no specific diet for PD that can treat the disease or any of the associated symptoms, nutritional intervention should be focused on the nutritional needs of each patient individually. These needs should be estimated according to the patient's age, stage, current disease symptoms, and other relevant nutrition-related pathologies such as diabetes, levels of physical activity (including physiotherapy), and nutritional status. Individual food preferences should also be considered.

A patient with PD should have a varied and well-balanced diet rich in fibre. Adequate fibre intake can be ensured by the consumption of a wide variety of vegetables such as broccoli, spinach and cabbage (whether present in soups or as a garnish for meat and fish), beans (such as peas, lentils, and broad beans), whole grain cereals (such as whole grain bread, oats, and breakfast cereals), fruits (kiwi, mango, plums, and oranges), nuts (such as peanuts and hazelnuts) and seeds (such as flaxseeds and sunflower seeds). All meals should have a source of carbohydrates such as bread, rice, potato, or pasta. At least four of the daily meals should contain a source of high-quality protein, namely meat, fish, eggs, or dairy.

The consistency of food should be adapted to the patient's swallowing and chewing capacities.

In early disease stages the nutritional goals are to contribute to the improvement of non-motor symptoms (such as constipation), to promote a healthy diet and hydration and to maintain a healthy body weight. In this stage the nutritional needs are very similar to those of an individual without PD.

For constipation, it is recommended:

- To increase physical activity according to the patient's capacity and medical recommendations;

19.FOODS TO EAT AND AVOID?

Diana Miranda and Joana Breda, *Nutritionists*

- To increase the intake of food rich in fibre;

- To increase the intake of fluids preferably water.

Hydration is crucial for promoting correct bowel function. It is recommended to consume 30ml of water per Kg of body weight daily (for instance, a person weighing 60Kg should drink 30 x 60 = 1800ml of water). Sugar-free drinks such as tea, juicy fruits such as watermelon, and sugar-free jelly can be used as good alternatives to increase fluid intake.

Disease progression, appearance of new symptoms (smell and taste dysfunction, for instance), and medication side effects such as dry mouth, can influence appetite, as well as the quantity and quality of nutritional intake.

Body weight fluctuation in patients with PD is frequent, although the underlying cause remains unexplained. Weight loss is more common in advanced stages but can occur in all disease stages.

Vitamin and mineral supplements (commonly known as food supplements) are not recommended, since an adequate diet supplies the minimum needs. Supplementation shows no additional benefits, except if a specific nutritional deficiency is detected in blood tests. It is important to keep in mind that the interactions between these supplements and medication are not all known. If the patient takes food supplements it is important that the doctor is informed.

To avoid food-medication interactions, it is recommended to take medication at least 30 minutes before meals and therefore adjusting eating and medication schedules may be needed. Patients with severe motor fluctuations (sudden change between ON and OFF periods) may benefit from separating the intake of levodopa (Sinemet® or Madopar®) and meals.

The role of the caregiver is essential in identifying alterations such as weight loss, constipation, diarrhea, appetite change, decrease in food and/or fluid intake, chewing and swallowing difficulties, and choking. These alterations should be presented to the doctor and, if necessary, to the nutritionist so that other nutritional strategies can be suggested.

20.HOW TO PREVENT CHOKING?

Rita Loureiro, *Speech Therapist*

Some people with PD may find it difficult to chew and swallow food, liquids, or saliva. This difficulty is called dysphagia and it should be suspected when the person with PD has:

- Difficulty chewing food;
- Difficulty swallowing;
- An accumulation of food in the mouth, after swallowing;
- A gurgling or wet voice;
- Difficulty taking tablets;
- Recurrent respiratory infections;
- Coughs and/or chokes when eating or drinking;
- A sensation of food stuck in the throat;
- Difficulty controlling saliva (drooling, coughing, or choking on saliva);
- Unintentional weight loss.

These symptoms are due to a weakening and a loss of control of the muscles needed for chewing and swallowing and might not be noticed by the person with PD. Therefore, the caregiver plays a key role in recognizing these changes and communicating them to the doctor or speech therapist.

20.HOW TO PREVENT CHOKING?

Rita Loureiro, *Speech Therapist*

In early disease stages, these symptoms may be mild or non-existent. With the progression of the disease, problems may become more severe and induce a significant impact on the person's life.

Changes in swallowing may cause:

- Respiratory infections (associated with aspiration pneumonias), caused by food or liquids entering the lungs;

- Malnutrition and dehydration, that is, not eating enough food and water to maintain health;

- Asphyxiation due to blockage of the airways by food, preventing the person from breathing;

- Decreased pleasure associated with meal times and increased social isolation.

When the person with PD presents these difficulties, the following are suggested:

1. **Ensure only small portions of food are put into the mouth**
Swallowing can be better controlled if small mouthfuls are taken. This also helps ensure that food is not swallowed without first being chewed properly. An example of how this can be achieved is using a small desert spoon or a teaspoon instead of a tablespoon or a fork. For liquids, a straw can be used ensuring that small pauses are made between each gulp.

2. **Make sure everything in the mouth has been swallowed**
before putting more food in the mouth. The person with PD should move their tongue around inside their mouth in order to remove all the pieces of food that have accumulated after swallowing, especially in the spaces between the teeth, lips, and cheeks.

3. **Avoid drinking or eating in a hurry**
Eating should be without time constraints, the person with PD must be allowed to take their time eating their meal in order to ensure that they can eat and drink both safely and calmly.

4. Swallow with strength and concentration
Swallowing should be done consciously by tightening the lips, tongue, and throat. This way, proper muscle contraction is favoured.

5. Take one tablet at a time.
People who take many pills may feel tempted to take them all at once in the same mouthful. This requires great capacity of coordination and can cause choking.

6. Take tablets with pureed food or a thick drink.
Instead of taking the tablets with water, it is easier with a thick drink (e.g. a smoothie) or a pureed food (e.g. a fruit puree).

7. Avoid eating and drinking when lying down, reclining, or with the head tilted backwards, as it decreases food control and makes swallowing more difficult.

8. Adapt your food (e.g. cut the food into small pieces, make soups creamier and mash very hard foods).

9. Avoid foods that crumble or spread around inside the mouth (e.g. biscuits, crackers, rice, etc.).

ORAL HYGIENE IN THE PERSON WITH PD

It should be noted that proper oral hygiene removes bacteria present in the saliva and prevents them from moving into the respiratory tract causing respiratory infections. In PD, there is a tendency for tooth decay, but its actual cause is not known. In order to reduce the risk of worsening oral health, the following are recommended:

1. Use a sponge or compress to remove thick or dry secretions;

2. Brush the teeth and tongue with a toothbrush and toothpaste. Patients who have lots of saliva may use a brush that has suction to lessen the likelihood of choking during oral hygiene;

3. If possible, rinse, or alternatively, clean the mouth using a sponge or compress with a non-alcoholic mouthwash;

4. It is also important to regularly clean any dental prostheses.

A speech therapist who works with those with swallowing difficulties can teach patients exercises and how to adapt food and liquids to help minimize and manage the difficulties that can be encountered.

21.HOW TO PREVENT FALLS?

Pedro Nunes and Alexandra Saúde, *Physiotherapists*

Falls can be frequent in people with Parkinson's disease (PD), and they often begin several years after the onset of symptoms. Falls are often due to factors associated with the disease, including freezing of gait (feet being "glued to the ground"), small steps, slowness of movement, balance problems, weakness, and decreased trunk mobility.

In addition to the physical consequences that a fall can cause, many people who fall develop a fear of falling. This fear can lead to self-imposed limitations affecting professional and social life, yet participation in professional and social activities can reduce the risk of future falls.

It should be noted that there is an increased risk of falls in those who have a history of falls or balance issues. The majority of falls occur at home when turning, standing up, bending forward, or when performing two tasks at once (dual tasking). In order to help prevent falls various adaptations of the home environment can be made, and the following safety strategies may be applied.

HOME ENVIRONMENT ADAPTATIONS

The home environment must be organized so that the person with PD can circulate at will and without danger of an accident. Therefore, the following points should be considered:

- Remove loose carpets/rugs;

- Take care when opening doors (the person with PD should be positioned close to the door so as to avoid stretching and losing balance);

- Facilitate access to the light switches and ensure the home is appropriately lit;

- Ensure that another person reaches objects stored in high places, so as to avoid the use of ladders or benches;

- Do not use spaces while wet or slippery;

- Use stairs with handrails;
- Prevent cats and dogs from circulating near people at risk of falling.

In the bathroom:

- Replace the bathtub and use the shower only;
- Use fixed support frames/bars;
- If necessary, use a support or sanitary chair for the shower;
- Use non-slip flooring.

In the kitchen:

- Create a space between furniture, including tables and chairs, to ensure safe circulation;
- Facilitate access to furniture;
- Arrange the kitchen tools at a medium height level;
- Do not stand in front or on the opening side of the refrigerator door.

In the living room, office, and bedrooms:

- Avoid low and deep sofas;
- Avoid wheelchairs (office);
- Use easily accessible beds (they should not be too high or too low);
- Remove excess furniture and organize the room so as to prevent stumbling on chairs, tables, or loose wires on the floor.

21.HOW TO PREVENT FALLS?

Pedro Nunes and Alexandra Saúde, *Physiotherapists*

It is important to mention that the adaptations can be modified according to the progression of the disease.

MOVEMENT STRATEGY

Family members and/or caregivers play an important role in the daily life of people with PD. Therefore, it is necessary that they learn some strategies that can be used to facilitate movement.

- Do not distract a person with PD with other tasks (e.g. talking or carrying a glass of water) while they are walking;

- Encourage the person with PD to count steps while walking and also to take big steps;

- Encourage the person with PD to bend his/her knees and to walk with the heels striking the ground first;

- Let the person with PD know when his/her feet start to drag;

- Ensure the person with PD does not walk backwards or picks up objects from the ground;

- Ensure the person with PD stops immediately when there are episodes of freezing of gait.

It is also recommended that people with PD wear comfortable and closed shoes, with non-slip soles to provide greater safety when walking.

Physiotherapy can reduce the number of falls in people with PD and therefore should be started as early as possible, preferably in the early stages of the disease. In this way, the rehabilitation programs are defined according to the needs of each person and can prevent falls, making the person capable of carrying out activities of daily life with a lower degree of dependence.

22. HOW TO DEAL WITH SEXUAL PROBLEMS?

Nuno Marques, *Clinical Psychologist*

What are "sexual problems"?

A more appropriate term for "sexual problems" is "sexual dysfunction". Sexual dysfunction describes situations that prevent people with Parkinson's disease (PD) and the couple from achieving and maintaining a mutually satisfactory sexual life.

Does sexual dysfunction occur in PD?

Yes. Sexual dysfunction can be due to different factors: it can be associated with PD itself, can be caused by medications (for PD or other health issues), can be due to physiological factors such as weakening sexual response due to aging, or psychological factors such as stress and anxiety.

In which situations can sexual dysfunction appear?

In the majority of cases sexual dysfunction occurs in a context of intimacy but can also appear in public situations (for instance, in the street, in stores, restaurants, or cinemas).

What are the symptoms of sexual dysfunction?

Sexual dysfunction may appear both in physical and psychological ways. Reduced agility of a person with PD may, for instance, harm their sexual performance. This limitation often leads to situations of sadness and anxiety. Other symptoms that can interfere with a person's sex life include excessive salivation, shaking, and excessive sweating.

From a psychological perspective, untreated sexual dysfunction may jeopardize a couple's relationship and lead to situations in which one avoids the other: people may sleep in separate rooms or even file for divorce. Men complain more frequently about erectile dysfunction, and women about lack of sexual desire.

On the other hand, people with PD may exhibit a hypersexualized behaviour (an excessive and permanent desire to engage in sexual activities). They can start to exhibit inappropriate sexual behaviours in situations – either public or private – when impulse control seems very difficult. It is important to mention that some medications used to treat PD (for instance, dopaminergic agonists) may elicit or facilitate these behaviours, and this should be reported to the neurologist at once.

22.HOW TO DEAL WITH SEXUAL PROBLEMS?

Nuno Marques, *Clinical Psychologist*

What to do in a situation of sexual dysfunction?

What to do differs depending upon the origin of the dysfunction. If a new medication or a modified dose of a current medication is suspected of being the cause of the inappropriate behaviours, this should be reported and discussed with a neurologist.

If the origin is related to the person or the couple, then psychological counselling should be sought if both feel that they can speak about the dysfunction in an open and comprehensive manner. Clear and honest communication is essential in overcoming psychogenic sexual dysfunction. For instance, adopting more comfortable sexual positions for the person with PD may compensate lack of mobility and agility; showing tenderness and affection in a "non-sexual" way (e.g. kissing and hugging) is also fundamental; sexual intercourse itself is just a small part of the wider sex life of a couple.

How to prevent sexual dysfunctions?

Once again, prevention of sexual dysfunction is dependent on its cause. If the cause is psychological then open and honest communication with the partner and the clinical staff (physicians, nurses, psychologists, physiotherapists, auxiliary staff) should be achieved. Through good communication the difficulties and taboos should be overcome, thus allowing a greater quality of life (sexual and general), which is fundamental to everyone's well-being – particularly those with PD.

23.WHICH PHYSICAL ACTIVITY?

Pedro Nunes and Alexandra Saúde, *Physiotherapists*

Motor symptoms have a great impact on the functionality and quality of life of the person with PD. The positive effects of physiotherapy (including clinical exercise) in PD have been demonstrated and consensually recognized by the scientific community. As a complement to pharmacological intervention, physiotherapy and physical exercise can improve mobility, gait, balance, and muscle strength. Exercises should be adapted according to the stage of the disease and the physical capacities of the person with PD.

At an early stage of the disease course the goal is to improve physical capacity, prevent secondary complications, reduce pain, and reduce fear of falling. Exercises are based on cardiovascular training, muscle strengthening, balance, bed mobility, transfers, and gait. The type of exercises can also be adapted to incorporate the training of complex motor sequences.

Here are some examples of exercises:

- **Cardiovascular training:** Nordic walking (natural walking is enhanced by walking with two sticks held slightly tilted backward), running, swimming, cycling, dancing – at least 30 min per day;

- **Muscle strengthening:** squats (in a standing position with the feet facing forward and hip-width apart, lower the hips downwards and backwards as if about to sit in an imaginary chair, bend the knees but keep them over the ankles—they must not go past the toes) – 3 sets of 15 repetitions, 2-3 times per week;

- **Balance training:** along a path, change the speed or the surfaces that are walked on (e.g., walk on grass, on sand, or on mountain paths);

- **Mobility and transfer exercises** (e.g., sit to stand at different heights, bed turning, and getting in and out of a car);

- **Stretching** (20-30 seconds, 3 repetitions).

23. WHICH PHYSICAL ACTIVITY?

Pedro Nunes and Alexandra Saúde, *Physiotherapists*

In the advanced stage of the disease, the goal is to prevent and manage the associated complications by performing general mobility exercises and safety strategies. The caregiver should be involved in the treatment of the person with PD and learn how to perform transfers, assist in changes of position and correct placements in the chair or bed.

Defining the intensity, frequency, and complexity of the exercises is fundamental in the rehabilitation process. The exercises recommended for a person with PD depend on the stage of the disease and on a careful assessment by the physiotherapist. However, several studies conclude that people with PD should perform, at least, a 45-min workout 3 times a week.

24.DO CAREGIVERS GET SICK?

Filomena Sousa, *Clinical Psychologist*

PD is a disease that not only affects patients but also their caregivers. In many cases, when caregivers are family members they have no idea what awaits them and how much their assistance will be required.

Caring for people with PD can be difficult, often requiring caregivers to reorganize their lives (manners, routines, or habits) compromising their well-being and leading to personal and emotional stress.

What does the caregiver feel?

The personal and emotional stress of the immediate caregiver is huge. Caregivers need to maintain their physical and emotional integrity in order to provide the necessary care. Caregivers should recognise their feelings and accept them as the normal process of psychological growth, this is essential for maintaining a good quality of life.

Caregivers may present complex and ambivalent feelings such as anger, guilt, fear, distress, confusion, fatigue, stress, sadness, nervousness, crying, fear of death, or disability. Often, these feelings occur all at once and need to be understood because they are part of the caregiver’s relationship with the person being cared for. In this way, it is important that caregivers understand their reactions and their feelings to know how to take good care of themselves. On the other hand, caregivers also need to understand that the people being cared for may have reactions and behaviours that may make it difficult to care for them (e.g., refusal to eat or bad hygiene habits) so they should manage their feelings of frustration without blaming themselves or others.

Taking care of others has consequences

Providing care for people with diseases such as PD can change the health of caregivers: depression, anxiety, psychosomatic disorders, sleep disorders, and chronic diseases are more likely to occur in these individuals.

The accumulation of physical, mental, and social exhaustion can seriously change caregivers’ quality of life and that of the people being cared for.

24.DO CAREGIVERS GET SICK?

Filomena Sousa, *Clinical Psychologist*

The social life of caregivers is often compromised and can lead to isolation and loneliness.

How to prevent caregivers' stress?

- Normalize the feelings that arise during the act of caring;

- Assign tasks to someone else (ask family members or others for help) and dedicate time to leisure (avoid sacrificing your own interests and activities);

- Talk with family members, with healthcare staff (doctor, nurse, psychologist, physiotherapist), or with other caregivers (this exchange of experiences can help increase understanding and acknowledgement of emotions, and it is a positive social activity);

- Recognize the signs of stress (anger, isolation, exhaustion, lack of focus, anxiety, and marked sadness) and when to ask for help (medical and /or psychological);

- "A different look" – caring can represent a sentimental retribution to those who cared for us. These interactions considered positive, are the main protector of caregivers' stress.

By improving how caregivers deal with the situations they face, and by ensuring emotional and functional stability, the journey of caregiving will be much easier.

REMEMBER

TO TAKE CARE
OF OTHERS,
YOU NEED
TO TAKE CARE
OF YOURSELF!

25.HOW TO DEAL WITH THE CAREGIVER'S BURDEN?

Erica Marcelino, *Clinical Psychologist*

Parkinson’s disease (PD) can have a major impact on a patient's family, especially those who are the closest and usually provide care. All stages of the disease can present a burden to the caregiver, from the recognition of the first symptoms and diagnosis to the emergence of physical, functional, cognitive, emotional, and behavioural changes. The progressive dependence (until the mourning stage) can also cause an enormous emotional, physical, and financial overload. A lack of knowledge about the disease can also cause anxiety, and it is important that the caregiver receives information, not only about the disease, but also about the available support services.

Families’ emotional response to the disease will depend on their ability to adapt. Emotional disturbances arise as the goals, expectations, and values of family members are called into question, which can lead to loss of control over emotions. The first feeling of loss can occur when the person with PD presents the first physical manifestations or functional losses (e.g., tremor, gait impairment, imbalance). There may be moments of greater sadness, anxiety, or fear as these symptoms remind family members of situations previously experienced with close relatives (e.g., a mother’s crippling illness).

Which factors increase the caregiver's overload?

The caregiver has the responsibility of not only supporting the person with PD in their daily tasks, but also of being an ally to the health professionals in the follow-up and treatment of the disease. When the loss of autonomy becomes more evident, the person with PD needs to be accompanied by people who provide them with security and who help them in the most varied tasks. Nevertheless, caregivers may feel tired or exhausted, especially when they devote all the time that they previously had for themselves to their sick family member.

Caregivers need to be aware of all this and ensure they can recognise and appreciate the changes in their relationship with the person with PD (emotional and conjugal) and other close relatives, as well as the changes that impact their relation to themselves (having less time for themselves, stopping taking care of their own health, giving up on plans and dreams, feeling lonely and, often, disconnected and isolated from the rest of the world). It is also important to consider the emotional impact of economic changes that may arise, due to the cost of care and sometimes due to loss of income.

25.HOW TO DEAL WITH THE CAREGIVER'S BURDEN?

Erica Marcelino, *Clinical Psychologist*

Not all caregivers approach this path in the same way. The disease is more easily accepted by some than others. Further, the ability to find appropriate strategies to respond to the needs and problems of patients with this disease varies considerably.

The emotional fragility of caregivers may generate feelings related to an incapacity to change, which must be followed by a healthcare professional in order to help them with the necessary transformations to reorganise themselves and make the necessary family arrangements.

In this regard, psychological support is essential for ensuring that caregivers find balance, either in the form of individual therapy (caregiver support therapy) and / or through support groups. The intervention of clinical psychology aims to improve the caregiver's health, thereby preventing situations of rupture that could lead to depression, anxiety, and stress, which harm the health of those who provide care and, consequently, the health of the person with PD.

It is very important that caregivers:

- Plan the day wisely, so as to not waste time. Routines should be established, and available resources identified (who can help, when, and how);

- Are reasonable and recognize their limits. Caregivers should learn to forgive themselves and close ones when things do not go the way they were expected to or desired;

- Take time for themselves (e.g. exercise, relaxation, family weekends where care can be delegated, going to the movies, theatres, and concerts, or just going for a walk, using caregiving services to allow relatives to rest);

- Take good care of their own health. Routine medical examinations are important. Caregivers should have the time to address their emotional needs and psychological well-being, so that they can express their feelings).

Caregivers should value their commitment and dedication but also their achievements and victories and try to smile, laugh, and have fun whenever possible.

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