

“STEPPING UP....”

A GUIDE FOR PEOPLE WITH PARKINSON’S



PARKINSON’S DISEASE AND MOVEMENT DISORDER SOCIETY.

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Dear friends,

Welcome to one more commemoration of Parkinson's on World Parkinson's day!
In all our programs the one thing we count on is our mutual interaction and your whole hearted participation. We take this opportunity to thank you for your support.

We have always received feedback from you on each of our endeavors and have sought to grow each time in directions that you have leaded us. It has been our experience that accumulating information to gain greater insight into your difficulties related to PD is a primary concern. With this booklet we hope to address this concern; allow you to understand your condition better, identify your areas of difficulty and related avenues for treatment and therapy, create more opportunities for exchange between you and your doctor and most of all involve you in every aspect of your care.

ABOUT THIS BOOKLET

This booklet is a guide to the different aspects of Parkinson's and its treatment. Our aim in this effort is to give you information and involve you in your care so as to ensure that you experience optimal benefits.

TABLE OF CONTENTS:

TOPIC	PAGE NO.
What is Parkinson's? -Understanding PD and its manifold characteristics	1..8
A Guide to Physical Exercises	9..21
A Guide to Improving Speech and Swallowing	22..31
A Guide to Diet and Nutrition	32..39
A Guide to the Medication	40..48
Caring for the Carers	49..51
New Directions <ul style="list-style-type: none">• Creating Support; Support groups• Yoga for Parkinson's• Young Onset Parkinson's• Reaching Out	52..57
Taking Control- Useful Strategies for Parkinson's	58..66



What is Parkinson's?

Understanding Parkinson's and its manifold characteristics

In collaboration with:
European Parkinson's Disease Association
Parkinson's New Zealand



PARKINSON'S DISEASE AND MOVEMENT DISORDER SOCIETY.



*What is Parkinson's?*

Parkinson's is a condition of the nervous system (a neurological condition) that is characterized by problems with body movements, although other non-motor symptoms can also occur. Body movements are controlled by nerve cells in the brain that pass messages to one another. These messages are sent using chemicals (neurotransmitters), which pass between the nerve cells and, in healthy people, the messages are carried smoothly.

One important neurotransmitter that is involved in controlling body movements is called dopamine. In people with Parkinson's disease (PD), there is a lack of dopamine in the brain, and therefore the relay of messages is disturbed, and this creates problems with the control of movement.

The symptoms of PD often appear gradually, usually on one side of the body first, and slowly progress over time. The main physical symptoms of PD are slowness of movement, stiffness, and sometimes tremor and loss of balance, although the type and severity of symptoms vary from person to person. Different symptoms may appear as PD progresses.

PD is globally distributed, affecting all cultures and races, with an estimated worldwide prevalence of 6.3 million people. More than 1 in 10 people with PD are diagnosed before the age of 50 years.

Although at present, there is no cure for PD, the symptoms can generally be treated effectively by using a variety of medications

*What are the symptoms of Parkinson's? How do they appear?*

In Parkinson's, the 3 most basic symptoms are; tremor (trembling or shaking), stiffness, and slowness of movement. These are called the Motor symptoms.

Other symptoms like; difficulties in maintaining posture and balance & problems with urinating and slow bowel movements, may also be experienced. These are the Non-motor symptoms.

As a result of these symptoms the smooth carrying out of daily activities and everyday routines may be affected. A characteristic of Parkinson's is that symptoms can change from day to day and sometimes even from hour to hour.

*What causes Parkinson's?*

In Parkinson's, there is a lack of a chemical in the brain called dopamine. Dopamine is that chemical messenger (neurotransmitter) which communicates the movement

instructions to the body. This lack of dopamine is because the brain has lost many of the nerve cells that normally make dopamine. Losing nerve cells is a completely normal process that occurs even in the healthiest person but, in PD, a very large number of the lost cells are from a specific part of the brain called the substantia nigra. This area is strongly involved with the control of body movements. Thus, resulting in movement difficulties, muscular stiffness, and tremor.

Medical experts are not yet certain what destroys these nerve cells or what causes some people to develop PD and not others. However, PD is not an infectious disease and it is not contagious.

The line of treatment for PD involves, drugs or medication, surgery for some cases, exercise & therapy and management and rehabilitation.

Coping with Parkinson's requires daily attention and regular medicines and exercise. Management of Parkinson's requires a multidisciplinary team, i.e. a team of Neurologists, General Practitioners, Physio Therapists, Occupational Therapists, Speech Therapists, Nutritionist, Psychologists, Social Workers & Parkinson's Organization.

What are the Motor Symptoms in Parkinson's?

There are three chief motor symptoms that characterize the diagnosis of Parkinson's. Most often they are called the Triad of symptoms.

1. Tremors; such a trembling of the limbs usually affects the hands and feet but may sometimes also affect the lips, tongue, jaw, abdomen and chest.
But, unlike tremors in other disorders, these tremors are called Resting Tremors- as they occur in the affected hand or foot when it is at rest and disappear during a movement.
2. Rigidity; or muscular stiffness is another hallmark symptom of PD. As a result, the affected muscle seems in a state of tension or contraction and is unable to relax even while at rest. This is responsible for the aches and pains in the body. Such rigidity is called Plastic or Passive rigidity- in that we find a constant uniform resistance to passive movement or manipulation of the limbs and muscles.
3. The third element of the triad, the slowness of bodily movements is called Bradykinesia. This involves not only slowness in carrying out a movement, but also hesitancy in initiating a new movement and fatiguing easily.
There appears to be a decrease in the performance of automatic movements like; eye blinking, swing of the arms while walking, hand gestures while talking, expressive facial movements etc.

Change in posture and difficulties in balance are 2 other important motor related symptoms that are associated with PD.

- Posture; many patients with PD tend to stand in a mildly stooped posture. Some may tend to lean slightly to one side. Another common tendency to carry one arm bent at the elbow. This tends to disappear if one makes the effort to swing one arm while standing or walking. While another more rare postural difficulty is seen in holding ones feet turned in slightly; usually while sitting when the legs are at rest.

Very often patients are unaware of these postural changes and maybe surprised to note them, say in their reflection. However, we must note that such awareness just puts them in a better position to work on these difficulties with exercises and sheer force of will.

- Balance; Patients with PD are often seen to not be able to maintain balance, as a result they may fall frequently, forwards or backwards. As a result, their balance maybe easily affected even by minor obstacles like; small elevations or changes in the floor like doormats, carpets pebbles etc. the difficulty also results in difficulties in carrying out tasks like wearing pants/trousers/pajamas or pulling up socks etc.

With time changes may come about in walking like; steps become small, shuffling of feet, difficulties with turning (in fear of loosing balance) etc.

Medications help bring some of the symptoms under control. And exercise enhances the effects of the medication and works to maintain muscle agility.

Exercises can reduce stiffness and improve mobility, posture, balance and help overcome problems related to balance and walking. It greatly improves the quality of our daily life with its direct affect on symptoms like stiffness and slowness. Not to mention improving our levels of fitness and sense of well-being.

Please note: Get your therapist/instructors advice before doing any exercises

What are the non-motor symptoms in Parkinson's?

As well as the main symptoms, PD can produce other symptoms that are not related to movement. Some of these are described below.

CNS- RELATED SYMPTOM:

CNS (Central Nervous System) - related symptoms are those which are caused by PD having an effect on messages sent by the brain to the rest of the body

Constipation:

Constipation is a common symptom of PD. It is caused by the muscles of the bowel moving more slowly than usual, together with the effects of less physical activity and/or a poor diet. This particular symptom is relatively easy to treat- either through the sensible use of diet and exercise, or by receiving medication from the doctor. It is also important to treat, as constipation can lead to other health problems and can reduce the effect of some medications, so dealing with it may actually improve function.

Drinking plenty of water (8-10 glasses) per day, is essential to help manage constipation, and other tips on using diet to avoid/ relieve constipation can be found in the guide to healthy eating/ nutrition manual included in this guide.

Sweating:

Sweating is one of the ways in which the body regulates temperature- the body cools down as water evaporates from sweat on the surface of the skin. Sweating is controlled by the nervous system, and PD (or PD medication) can sometimes interfere with this process, causing the body to produce either too much or too little sweat. If changes in sweating occur then a doctor should be consulted about how to manage the situation- for example, advising on fluid in take, room temperature, or skin moisturizing products.

Pain:

From time to time, People with PD may experience cramps, aches and feeling of numbness, coldness, or burning. This most frequently occurs in legs, although lower back pain and head aches are also common.

There are many ways in which pain can be eased without using medication, and a physio therapist will be able to provide specific recommendations for each person. Common strategies are, gentle exercise, massage and correct use of practical devices such as special cushions or mattresses. Other home remedies or external pain relief gels/ointments maybe discussed with your doctor.

Speech and Facial Expressions:

Communication between people is an important part of everyday life- making connections outside the home, as well as within the family. This type of communication involves many aspects, including words, body language and the manner of speech. In people with PD, slow or reduced movement of the muscle can result in the face showing less expression than usual. These symptoms can sometimes make communication more difficult, and can be misinterpreted as annoyance, disinterest, or as a lack of understanding. Changes to the function of facial/throat muscles can also affect the voice in some people with Pd, producing speech that may be quiet, hoarse, hurried or hesitant. Therefore, it is important that any changes are understood and managed promptly and effectively.

Your doctor will be able to recommend a speech and language therapist to help With effective tips and exercises for minimizing any speech problems. Advice on good posture, exercises to strengthen the vocal/facial muscles and general guidance on communicating clearly can all help to manage the situation. Some such exercises and tips can be found in the speech therapy guide attached with this guide.

BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS

Sleep

Some people with Pd find that they have trouble sleeping, possibly because one of their symptoms makes it difficult to feel restful, e.g., pain, stiffness or anxiety. Alternatively, sleep may be affected by a PD medication, or the changes in the brain that happen during PD itself.

It is very important for a person with PD to have enough sleep, as it can help to improve some symptoms, as well as benefiting health in general. The technical term for this is 'sleep benefit.'

Fatigue

Fatigue is physical and/ or mental exhaustion that is very common in PD. It may in fact be one of the first symptoms to appear.

Fatigue can be caused by one or more factors, including drug treatment, the extra effort of managing PD symptoms, disturbed sleep, or depression. Alternately, fatigue maybe produced directly by the chemical changes in the brain that occur in PD.

It is important to identify the cause of fatigue. For example, if fatigue is associated with depression, then the depression should be treated; if it is caused by sleeping problems then they should be assessed and treated. Fatigue, that is caused directly by PD maybe treated by PD medication.

Aside from drug treatment, coping methods for fatigue include:

- Allowing more time to complete daily activities
- Learning to recognize times when medication is most effective and fatigue is reduced, so as to schedule most activities during that time.
- Ensuring that the daily diet is balanced, providing energy, and avoiding constipation (which can cause tiredness).
- Using assistive devices, example dressing aids remote controls etc. which make daily activities less tiring.
- Taking regular gentle exercise to keep muscles active.

Mood/ Depression

A change in mood is a natural reaction to being diagnosed with PD, or developing a particular symptom. However, depression in PD can also be caused by the disease itself lowering the levels of chemicals in the brain that control mood. Signs of depression include a negative view of oneself, the environment and the future; loss of motivation, energy, and interest (including social and sexual); poor sleep and memory; and a decreased appetite.

Depression is a treatable condition and, because it can have such a big impact on everyday life, it is important that the doctor is told about any mood changes in order to provide prompt treatment. In addition to relieving depression, it can improve a person's

response to therapy for other PD symptoms, and it can also offer relief to the caregiver, who may find it more difficult to offer support to a person who is depressed.

Often the Person with PD and caregiver benefit from counseling services and other forms of increasing emotional support.

Anxiety

Anyone who experiences a new or stressful situation may become anxious. Anxiety disrupts sleep, and can also worsen PD symptoms such as tremor. Extreme anxiety can produce panic attacks, which include periods of dizziness, shortness of breath, and sweating. Anxiety maybe experienced as a constant feeling or it maybe triggered by certain situations, going out in public. In addition to these triggers, anxiety may also be a sign a depression.

People with PD can be taught relaxation methods, and often find that therapy such as breathing techniques, muscle relaxation, massage, meditation, yoga, aroma therapy, Tai chi etc, can help to relieve anxiety. In some situations, medication maybe advised by your doctor.

Thought and Memory.

Because PD affects more than one part of the brain, some people find that they experience changes in thought and memory, in addition to the more common movement-related symptoms. In early PD, these may include difficulty with concentration or subtle changes in memory and thinking- often barely noticeable to the person with PD. The ability to plan complex tasks or perform several tasks at once may also be affected. These impairments may gradually progress along with other symptoms of the disease, although it should be noted that medications can also have an effect on thought process (e.g. producing confusion or hallucinations), and so any changes should be reported to your doctor as soon as possible to determine the cause.

What are Motor Fluctuations?

In PD, there are times when symptom control is good and the medication seems to be working well- this is called the “ON” time. At other times, symptom control may be poor with symptoms not appearing to respond to medication- this is called “OFF” time. Motor fluctuations refer to a state where a person with PD changes between ON time and OFF time. This situation maybe common in people who have been receiving levodopa treatment for many years. Another change in symptom control is seen at the peak of levodopa absorption, when a person may experience restless movements known as dyskinesias- almost as if there was ‘too much’ movement.

- Wearing- off is a phrase commonly used to describe the period of time between the end of the effect of one dose , and the beginning of the next one. That is, the beneficial effects of the previous dose appear to be wearing off.

- Wearing off is relieved by taking the next dose of levodopa- although there is often a delay of about 1 hour before the drug takes effect. A doctor maybe able to reduce the effects of wearing off by recommending;
 - ✓ Smaller, but more frequent, levodopa doses.
 - ✓ A different form of levodopa that releases the drug more gradually
 - ✓ Chewing the levodopa tablets or taking them with carbonated drinks to increase the speed of their effect.
 - ✓ Not taking levodopa with meals.
 - ✓ Treating constipation.

Another alternate is to add another drug (MAO-B inhibitor/ dopamine agonist/ COMT inhibitor) to minimize the wearing off symptoms. Such an addition of another drug is called adjunct or combination therapy.

Treating motor fluctuations is a complicated process and needs to be tailored to each individual's symptoms & dosages. Thus it should be done with the advice of your doctor.

You can help your doctor understand the fluctuations you experience by maintaining a wearing off record. A sample of such a record is provided in the 'taking control' section of this guide.

Parkinson's Disease Improving Mobility

A Guide to physical exercises for PD

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BASIC GUIDELINES:

The first line in the treatment of Parkinson's disease today is drug therapy, but treatment does not stop there. The management of Parkinson's disease involves physical therapy, occupational therapy and speech therapy. Exercises are an adjunct, and not substitute for drugs. The booklet contains few "self-help" exercises to get you started. You can contact your physiotherapist for custom-made exercise programme.

In Parkinson's disease there is rigidity or stiffness of muscles and a tendency to not to move all the joints of the body. If exercises are not done regularly, joints become stiff and painful. It is a normal tendency of patients of Parkinson's disease to withdraw from their usual activities. It is very important

- to keep as active and as fit as possible and to maintain as normal a routine as you can physically and socially
- to develop a hobby, to participate in outdoor group activities like group walking, joining a laughter club etc. according to your interest.
- to do exercises in moderation and not to tire or exhaust oneself.

Remember the old adage:

Use it or Lose it.

So Get Started.....



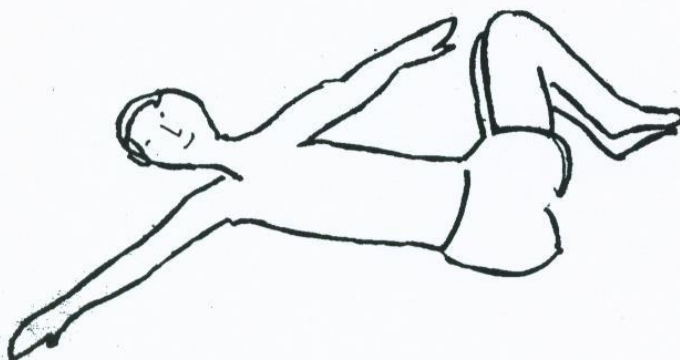
Bending the knee, draw up right leg towards the chest. Rock the knee towards chest few times. Then lower & the repeat with other leg.



Bend both the knees towards the chest & Rock gently.



Raise both the hips, hold for count of 3 then lower the hips down.



Turn both the knees to the left. Then repeat the movement towards the other side.



Starting Position :
Lying on back, legs drawn
up, knees bent.



Breathe in raising both arms,
stretching them beyond the head
on the floor.



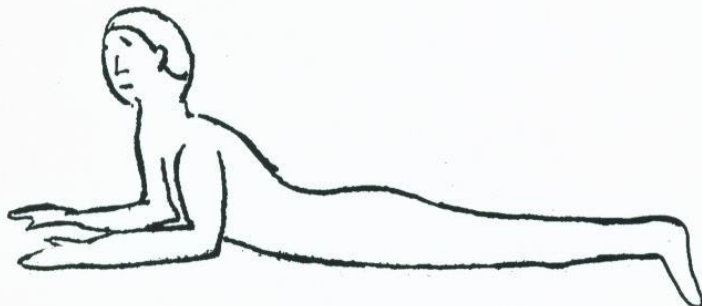
Bring arms down extending them
sideways to the floor at shoulder
level while breathing out, then
revert to starting position.



Hands on thighs, lift the head and shoulder up and slide hands up towards the knees. One should not experience pain in the neck.



Lying face down, palms underneath the shoulders.



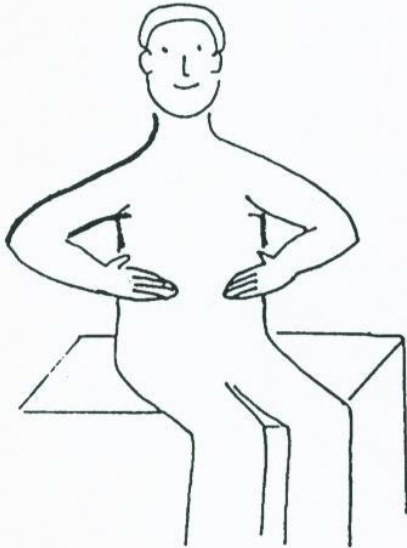
From above position, Raise the chest up.



Inhale (take breath in) while taking arms up.
Exhale (breath out) while bringing arms down.



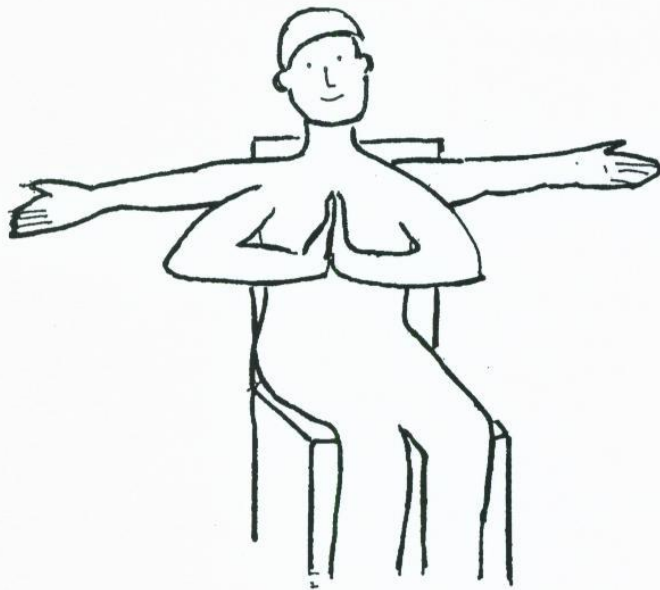
Sit upright on a stool. Without bending your arms, turn the body waist upwards first towards the left, then to the right. Balance the arms simultaneously in opposite directions.



Breathe in deeply, but easily and feel the ribs move out, i.e. against your hands. Do not move your shoulders. As you breathe out, squeeze it out with your fingertips.

Other Exercises :

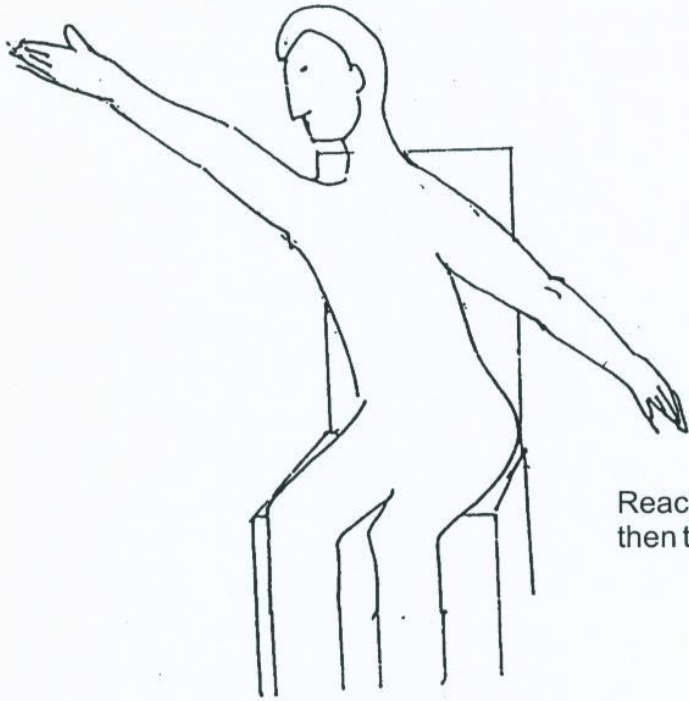
- 1) Practising different facial expressions.
- 2) Incentive spirometer (for breathing)



Sitting erect, press hands together. Brace shoulder blades together stretch arms out at 90°



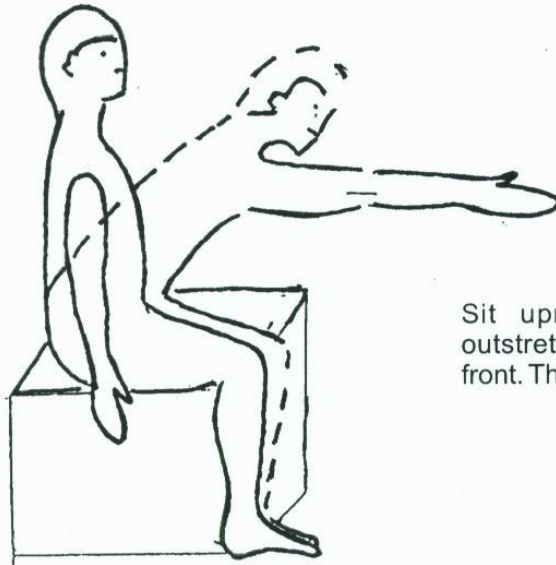
Raise both the arms up. Thumbs should be pointing upwards. In sitting bring the shoulders slightly forwards on the hips.



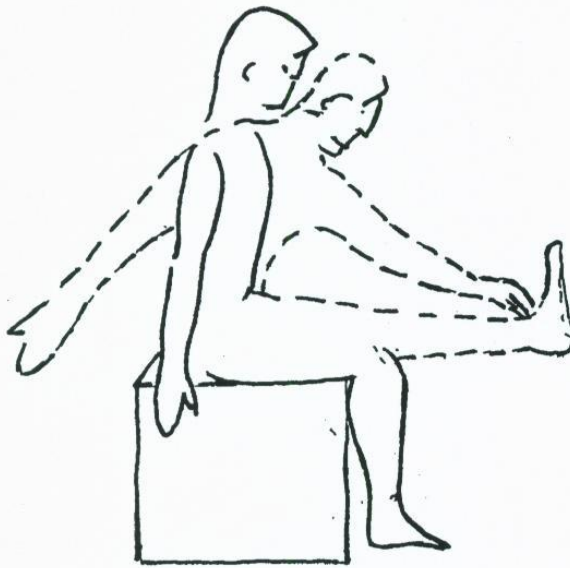
Reach sideways to right and then to other side.



While getting up from stool/chair: come forward in the stool. Let feet be firmly on the ground. Bend forward from waist and then get up.



Sit upright on a stool
outstretch your arms in
front. Then, reach in front.



Sit on a stool, come
forwards from waist, so that
left hand touches right ankle
as shown.



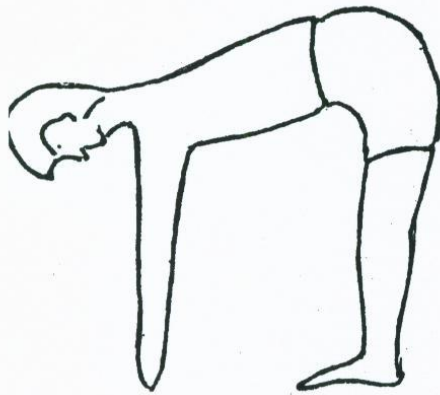
Sit on a stool, feet
supported. Bend forward at
the waist, till right hand
touches left toes.



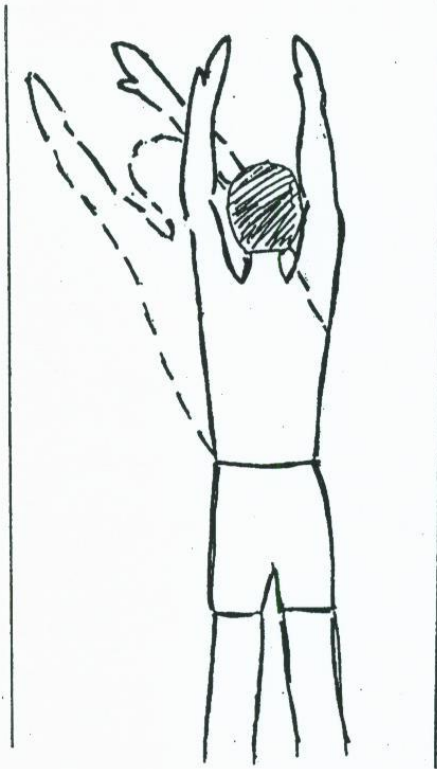
Stooped posture.



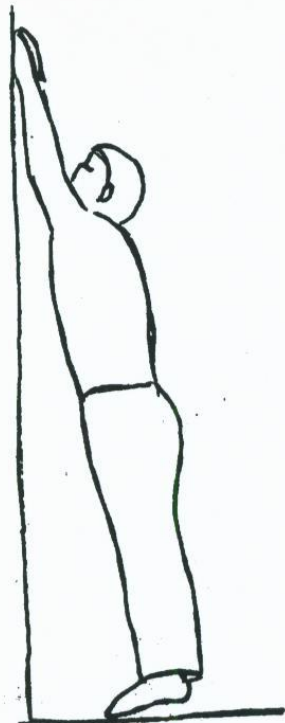
Stand against the wall and try to make yourself as straight as possible.



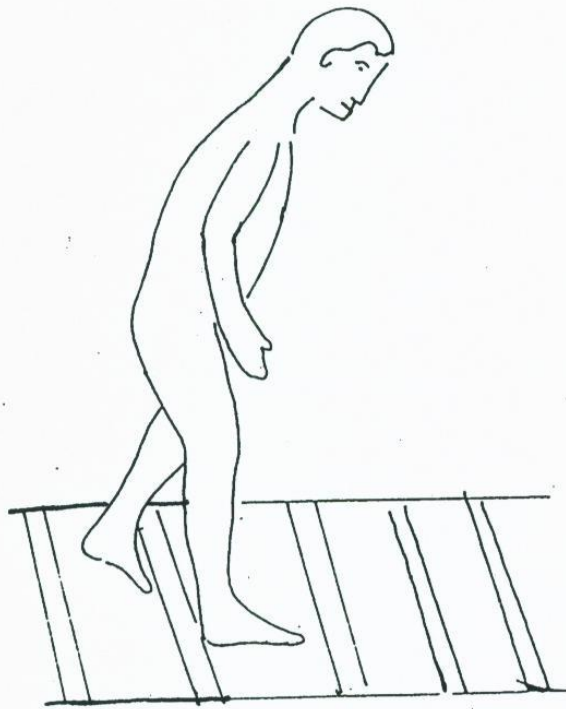
Breath out, as you go down to touch the floor.



Stand facing the wall.
Stretch sideways.



Reach upwards and then lift
the heels off the floor.



Stripes can be painted on the floor to help the patient walk easily.

A GUIDE TO IMPROVING SPEECH & SWALLOWING

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Can I improve my speech and swallowing?

This must be a question that most of you may have in your minds. Maybe, some of you have not even thought of entertaining this question in your mind assuming that there is no scope for improvement. Well, there is a lot you can do to improve the situation. The following explanations and guidelines we hope will be of good help.

How to cope, adjust and compensate for your speech (communication) and swallowing challenges?

Speech problems can be seen as part of Parkinson's Disease and when severe, can make oral communication very difficult if not impossible. Problems often begin with the speech becoming softer and more monotonous in quality. Some may even develop a stuttering like quality to their speech.

Individuals with Parkinson's Disease are likely to report about the following difficulties in speech and swallowing:-

1. Voice is quieter, or weak, or cannot be heard in noise.
2. Many will complain that rate of speaking is too fast or that words are not clear
3. Some feel that their speech lacks emotional tone.
4. Some describe the difficulties with initiation of speech or repetitions of sounds, syllables, and even words.
5. Speech is poorer when tired.
6. Speech varies as a function of their medication cycle, often reporting that it does get worse just before their next dose.
7. Sometimes upper lip is stiff
8. Often have complaints of drooling and swallowing
9. Greater time and effort to move food or liquid from the mouth to the stomach

Therefore it is important for a person with Parkinson's Disease and his/her family members to understand why he/she experiences these problems with communication that is, speech. The reason for the swallowing problem, if understood, also helps in coping with it.

First it is essential to realize that speech involves the *movement* of a large group of muscles in the various systems of our body and that all these muscles need to co-ordinate

in a complex way with proper timing and rhythm. Therefore, we will first highlight the various systems / processes involved in the production of speech followed by the constraints you may experience in each of the systems which may contribute to your speech problem. These are

- RESPIRATION
- PHONATION
- RESONANCE
- ARTICULATION
- PROSODY

1. RESPIRATION: - What is the relationship of BREATHING AND SPEECH? Breath is the main source of power for the production of speech. During normal respiration air gently gets into the lungs passing through the nostrils (nose), pharynx (space behind the oral cavity and nasal cavity), larynx (voice box) and trachea (wind pipe). Similarly air gets out of the lungs passing through the trachea, larynx, and pharynx and through the nostrils to the outside air. It is when this air passes through the voice box that the vocal cords (2 strings like muscles- parallel to each other in the larynx) vibrate to produce the sound. Adequate power is possible if the chest and abdomen muscles move adequately and precisely in coordination. The duration of the **inspiration phase** (breathing in) and the **expiration phase** (breathing out) are the same when one is quiet (known as vegetative breathing) but gets modified during speech known as speech breathing. The duration of the expiratory phase is longer during speech and this control of prolonging the expiratory phase is possible due to the control of the movement of a group of respiratory muscles. The whole process is complex but automatic and we therefore take it for granted. The following are the constraints for you during the process of respiration:-

- **Reduced chest movements**
- **Rapid breathing cycles**
- **Inability to shift from vegetative breathing to speech breathing**

Needless to explain that this happens due to rigidity, which in turn reduces the **range of movements** of the abdominal and chest muscles and makes it difficult to **initiate movements**.

Additionally, some of you may have **incorrect postures** wherein you may stoop or hunch your shoulders while walking, standing or sitting. These postures may restrict your breathing, preventing deep breathing leading to a shallower pattern of breathing not conducive for good speech.

2. PHONATION that is, production of the voice is possible, as discussed above, if there is sufficient power in the air stream that is being expired. Besides, the cords need to move in a coordinated manner with sufficient force to produce an adequately loud voice. Once again due to rigidity, **reduced range and slowness of movements** lead to reduced flexibility and control of laryngeal movements which in turn leads to inappropriate postures of the vocal cords and other structures in the larynx. Therefore the voice sounds **breathy, harsh, reduced in loudness and speech becomes monotonous**.

3. RESONANCE is the ability of some of our speech sounds to get amplified and or modified by the chambers the sound passes through. Our basic speech sound produced at the larynx passes through the nasal cavity and oral cavity. Depending on the type of speech sound the size and shape of the oral cavity keeps changing and so does the sound. When the air passes through the nose, the speech gets the nasal sound like in 'mama' and 'nana'. The soft palate is the part which is responsible for giving the oral tone or the nasal tone. When the soft palate moves up against the pharynx, it closes off the nasal resonance by blocking air from passing through the nasal cavity. This forces air out through the oral cavity thus producing oral tone leading to sounds such as vowels and non nasal consonants. When the soft palate moves down, the nasal tone is produced wherein air is released both through the nasal as well as the oral cavity.

In some of you, the voice may sound hyper nasal due to the weakness and inability of the soft palate to move up adequately. However this found to be rare.

4. **ARTICULATION**, which is ability to move the various parts viz. tongue, lips, teeth, soft palate, jaws (known as articulators) and make appropriate contacts among a pair of articulators in proper rhythm and optimum speed to produce speech that is easy for the listener to understand. If the contacts are inadequate the speech becomes unclear. Restricted movements of lips, jaws can make the speech too fast- (rushes of speech), too slow, inappropriate stress, frequent silent pause.

5. **PROSODY**: The ability to use intonation (emotional tone in our voice) is the result of the ability to fine tune the length of muscles of our vocal cords for making our voice high pitched or low pitched to add the liveliness to our voices. A voice can be made high pitched by tightening the vocal cords and can be made low pitched by keeping the cords lax. Similarly, varying loudness of our voice needs varying amounts of breath power. The foregoing is a simplistic explanation as the range of pitch and loudness varies with every phrase that we speak and therefore the changes are ongoing.

Similarly, appropriate facial expressions also need the fine control on the various groups of facial muscles and the contraction and relaxation of these muscles help to give the relevant expressions.

Thus both these abilities of having a good intonation and facial expressions get compromised due to the rigidity of the required muscles and you may have an expressionless face and a voice which lacks rhythm and variability and therefore sounds monotonous.

Process of Swallowing:-

To understand why swallowing may become a challenge, we will explain the process of swallowing:-The process of swallowing has typically the following four phases.

- 1) **The Oral Preparatory Phase** during which the food is accepted into the mouth and then the activity of chewing and tasting is followed by the manipulation of the food into a bolus (a cohesive mass).

- 2) **The Oral Phase** is the stage wherein the bolus is pushed posteriorly until the next swallow phase is initiated.
- 3) **The Pharyngeal Phase** begins with the triggering of “swallow reflex” This in simple terms means that our centre in the brain responsible for the movement of the bolus into our pharynx gets activated. There are 3 pre-requisites for this to happen which are:
 - a) Soft palate (velum) has to move up and backwards (in technical terms elevate and retract)
 - b) Larynx has to move up and forward.
 - c) Epiglottis (a flap of tissue that sits at the base of the tongue) should cover the larynx to protect it from food entering it.

Due to the above movements there is a pressure on the bolus and it moves down to the area just above our esophagus.

- 4) **The Esophageal Phase:** - Begins when the bolus enters the area just above our esophagus and ends when it enters into the esophagus.

In all the above stages, the passage of the bolus is facilitated by wave like movements of the inner lining of the muscles (technically termed as peristaltic movements) of pharynx and esophagus.

It is clear from the above, that your difficulty with swallowing is mainly due to the slowing down of your movements. One need not imagine it to be a major problem. Therefore if you start accepting that you will take longer to complete the whole process as compared to the time you took earlier, it will facilitate coping and adjustment on your part.

Difficulties that some of you may experience due to problems in Swallowing :-

- Drooling because you do not swallow frequently and saliva gets accumulated.

- Difficulty in chewing and pocketing of food in buccal recesses (inner side of cheeks because all the oral muscles move slower due to rigidity).
- Pumping movements of the tongue which are undesirable prevent the food from moving from front to the back of the mouth. These occur probably due to the attempts to swallow against all the odds. This leads to the difficulty in getting the swallow started.
- Food may stick in the pharynx and esophagus.

MANAGEMENT

There are several reasons why family members and the person with PD need to **first realize the difference of communication versus speech.**

1. We speak because we need to **communicate** our thoughts and feelings to others and we do so by not only using **speech** but often using gestures along with speech. We also use the channel of writing to express. Thus, speech is one of the modalities through which we communicate our thoughts.

2. Therefore depending on the degree of severity of speech disorder, one can take the additional support of the gestural and written channels/modalities to enhance communication and thereby make it relatively more efficient. Individuals with P.D. may need to repeat or answer questions that clarify the meaning of what they say, supplement speech by pointing to the first letter of each spoken word on a letter board, write or type portion of messages, and so on. This realization helps to shift the focus from speech to other channels/ modalities.

3. Therefore it will be good if one gets a clear picture of the following **aims that therapy will help them achieve:-**

a) We need to **compensate** for the functions that have become difficult. This is possible because we can modify the network of circuits in our brain that have been functioning optimally till now. With exercises we will try to change these very circuits and **maximize the residual abilities of the brain.**

Research has shown that we use only a small area of the brain during our lifetime and the rest of the areas have not been put to use. It is now that an attempt could be made to utilize these areas by doing **REGULAR EXERCISES** which a Speech Language Pathologist can assist you in.

b) We need to **accept the limitations** and accordingly adjust to the changing situations. These changes may continue as the difficulties increase.

c) **Medications** will help to improve your ability to speak at certain periods during your medication cycle. The speech is known to be better during the 'on state' of the medication.

TIPS TO IMPROVE SPEECH

- Express in short concise sentences.
- Exaggerate the sounds.
- Lay more stress on the key words.
- Take a breath before speaking.
- Make sure that you speak fewer words per breath.
- Open your mouth adequately.
- Try to speak as loudly as you can.
- Speak only in an environment which is less noisy. Family members need to pay special attention to this aspect.
- Singing is a good form of vocal exercise.
- Practicing deep breathing and exercise your respiratory system
- Lift your head up and do exercises to strengthen your posture if you have a posture where you tend to stoop over with your chin down on the chest. This will help to speak OUT clearly.

Regular speech exercises are the key to improve loudness and lend clarity to your speech. But, these exercises must be done regularly (**everyday**) or any benefits gained tend to be lost soon. In the event that speech really becomes compromised and exercises are not helping to produce understandable speech, then an alternative strategy of using

gestures, communication boards, signs can be taught to ensure that the individual is able to communicate. Some times a personal amplifier system may be of help to take care of speech which is very soft and exercises are not of much help. A speech language pathologist (SLP) is the member in the team to help you decide which device might be most suitable to your needs, abilities and lifestyle.

One speech pathologist, Dr. Lorraine Ramig, has long studied the effects of Parkinson's disease (PD) on the voice. Her research has shown that the vocal cords of individuals with PD become almost bowed () whereas to produce clear sound, the vocal cords must come together equally and totally ||. With regular exercises, the muscles of the vocal cords can become stronger and work more as they should. Dr. Ramig has found, however, that vocal exercises must be regular and continuing or the beneficial effects will soon wear off. The vocal cords are some of the most finely tuned muscles in the body. So, just like every other muscle, the vocal cords need regular, daily exercise to maintain proper function.

ROLE OF SLP AS A SWALLOWING THERAPIST.

The SLP focuses on four main domains to help you decrease your problem in swallowing -

- **Postural changes**
- **Changing consistencies of food**
- **Teaching Swallowing maneuvers**
- **Introduce changes in environment**

POSTURAL TECHNIQUES: - The following are some of the postures that an SLP will recommend depending on your difficulty.

Head back, Chin down, Head rotated to either left or right side.

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CHANGES IN THE CONSISTENCY OF FOOD

The SLP will advice on the various types of food you would find easy to swallow. Generally the ranges of consistencies you will need to look at are listed in the table below:-

CONSISTENCY	EXAMPLES
Thin liquid	Milk, fruit juice
Thick liquid	Soup, milkshake
Puree	Yogurt, custard
Soft solid	Mashed potato, idli, porridge, khichdi, upma
Hard solid	Biscuits, chappati, toast, salads

The SLP will observe your swallowing and give you the appropriate advice.

SWALLOWING MANEUVERS:- There are a few exercises which will strengthen your musculature like the pushing exercises done in a particular way or tightening of your neck muscles and lifting your larynx. It is difficult to describe and explain in print. It is advisable for you to do the recommended exercises under the supervision of an SLP.

CHANGES IN THE ENVIRONMENT:-

The family members should ensure that they communicate with you in the least noisy environment. They need to give sufficient time to you to answer when in conversation and not hurry you up. There should be least distractions while you are eating as you need to give your complete attention to your food, chewing and swallowing and do all the activities in a relaxed manner. A light music being played in the background will always ease a situation during meal times. Use utensils which have a better grip during cooking or eating.

SOME USEFUL TIPS TO IMPROVE SWALLOWING

- Develop the habit of consciously swallowing every few minutes if you have the tendency of saliva accumulating in your mouth. Carrying a bottle of water and taking a sip every few minutes can be tried to further facilitate the disposal of saliva.
- Eat fruits/vegetables cut in smaller pieces (same for non-vegetarian food)
- Take small morsels
- Swallow 2/3 times after each morsel
- Drink liquids carefully
- Thicker liquids may be easier for some
- Make sure you have enough time. Do not try to rush during meal time.
- Eat food at a time when the medication has its effect.
- In spite of following all the exercises and guidelines if your difficulties persist, you need to consider changing your diet in consultation with the Dietician and SLP

Hope these simple guidelines will help you face the challenges with confidence.

Wishing you good luck. Feel free to contact us at the address given below.

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Nutritional Value

A guide to diet and nutrition in Parkinson's

We acknowledge the contribution of:

Ms. Salome Benjamin

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Dept. of Medicine & Endocrinology

TNMC and Nair Hospital.



PARKINSON'S DISEASE AND MOVEMENT DISORDER SOCIETY.



NUTRITION IN PARKINSON'S DISEASE

INTRODUCTION:

Diet plays an important role in the lives of people with Parkinson's disease (PD).

Through the correct diet and nutrition one can:

- Maintain optimal nutritional status of the patient.
- Ensure optimal absorption and effectiveness of PD medication.
- Provide relief from symptoms such as constipation, weight loss/ gain etc.
- Provide relief from the side – effects of medication such as nausea, abdominal bloating etc.

The above goals can be achieved by taking help of Dietician. A Nutritionist would assess one's energy and protein levels and requirements based on the present nutritional status of the patient, age of the disease, grade of nutrition, individual tolerance to proteins and drug dosage.

NUTRIENTS & FOOD GROUPS

A thorough understanding of what constitutes a healthy diet can be obtained by understanding two basic concepts of Diet and Nutrition viz. Nutrients and Food Groups.

Nutrients are basically divided into *Macro – nutrients* (**Carbohydrates, Protein and Fat**) and *Micro – nutrients* (**Vitamins and Minerals**).

All foods fall into five basic Food Groups and each food group consists of a varied amount of nutrients.

1. **Breads, Cereals, Rice** contributes mainly carbohydrates, besides fiber, and some protein, calcium, iron, and B vitamins.

Ideally one requires around 6 – 11 servings per day.

2. **Fruit and Vegetables** provide vitamins and minerals (Vitamin C, carotenes, and folates), besides the most important fiber and water content and some carbohydrate, due to which they have fewer calories.

2 – 4 servings of the fruit group and 3 – 5 servings of the vegetable group should suffice.

3. **Meat, Fish, Eggs, Nuts, Pulses, Lentils** provide mostly protein with some fat, and vitamins and minerals including iron, zinc, magnesium and B vitamins.

The requirement is 2 – 3 servings per day.

4. **Milk and Dairy products** contain carbohydrate, protein, fat, and some vitamins and minerals, including vitamins B12, A and D. Calcium, an extremely important mineral is provided through this food group, more so in PD because there is an increased risk for osteoporosis.

3 – 4 servings per day are required.

5. **Extras** that include oils, sweets, cream etc include fat and sugar content. Though not a daily requisite, this food group can be used with PD patients who are experiencing weight loss to increase their calorie intake, and also to provide any extra energy needed by the body.

Anywhere “between” 1 – 7 portions may be required depending on the needs of the particular individual.

Along with these daily-required servings, the intake of FLUIDS, mainly water is an essential part of a healthy, balanced diet.

One should take at least 8 – 10 glasses of water everyday.

SERVINGS / PORTIONS

Knowing what constitutes **one (1) serving or portion is extremely necessary** and makes it easy to incorporate with the following examples that have been provided:

In the first group, where 6 – 11 servings per day are required, you could choose ONE serving from either of the following:

1 slice bread	½ chapatti	½ cup / 2 tbsp cooked rice
3 tbsp breakfast cereal	1 plain biscuit	3 tbsp cooked pasta/noodles
2 small boiled potatoes	1 medium baked potato	½ bread roll or muffin

When eating from this group, one should mostly attempt to choose whole grains foods over refined flour and grains, for example whole-wheat bread over white bread or whole-wheat pasta over refined flour pasta.

In the *second* group of fruits and vegetables, one could choose ONE serving from either of the following:

3 tbsp cooked vegetables	½ cup chopped raw vegetables	1 cup raw leafy greens
1 small side salad	1 small glass fruit juice	1 apple/ pear/ orange/ peach
2 plums	½ cup/ 7 berries / cherries	12 - 15 grapes
1 small banana	1 bowl papaya/ watermelon	¼ cup dried fruits

In the vegetable group one should include more *thoroughly* washed green leafy vegetables, as well as red, yellow and orange vegetables. In the fruit group, more importance should be given to citrus fruits and berries and cherries. Papayas are good for relieving constipation.

In the *third* group of meat, nuts, pulses, one could choose ONE serving from either of the following:

1 cup / 4 tbsp cooked lentils, dal, or pulses.	2 eggs	2 slices cold cuts / 2 sausages
60 gm cheese	6 – 10 nuts	60 – 90 gm meat / poultry
140 gm fish	30 gm peanut butter	110 gm Soya chunks/ tofu

To take your daily requirement of the *fourth* group of milk products, one could choose ONE serving from either of the following:

1 cup / 200 ml milk	1 bowl yoghurt	1 bowl rice pudding
120 gm paneer / cottage cheese	30 – 40 gm soft/ hard cheese	

The *fifth* group of ‘extras’, which are to be taken if required, include the following, and one could choose ONE serving from either of the following which consists of 50kcal/ serving

1 tsp butter/ margarine	2 tsp jam/ jelly/ marmalade/ honey	1 tsp cooking / salad oil
2 tsp/ cubes sugar	1 mug hot chocolate drink (made with water)	1 tbsp mayonnaise

Following table that is equivalent to THREE servings of foodstuff that one may generally eat has been provided for further help:

1 bar chocolate (30 gm)	1 packet wafers/ crisps (25 gm)	½ small slice cake (60 gm)
1 avg. scoop ice - cream	1 croissant	½ donut
2 cream – filled biscuits	1 small glass wine	30 ml spirits (scotch, whiskey etc)

SPECIAL CONSIDERATIONS FOR A PATIENT WITH PD

1) FOOD – MEDICATION INTERACTION

In PD, the food – medication interaction mainly constitutes protein – levodopa interaction. Foods rich in protein include meat, fish, nuts, and pulses. The mechanism with which these are absorbed into the blood stream are the same, and therefore, they compete with each other for absorption, often resulting in protein being absorbed, and the medication not providing the optimal effects. To avoid this one could take one of the following precautions/ steps, but only after consultation with ones Neuro physician/ Registered Dietician.

- Medication should be taken an hour prior to meals
- One could follow either of the following methods of protein distribution for optimal levodopa effectiveness:

	PLAN I PROTEIN INTAKE DISTRIBUTION (E.g. 40gm)		PLAN II PROTEIN INTAKE DISTRIBUTION (E.g. 40gm)	
BREAKFAST	1/4th	10 gm	1/3rd	13 gm
LUNCH	1/4th	10 gm	1/3rd	13 gm
DINNER	1/2	20 gm	1/3rd	13 gm

Decision between these two methods of distribution depends on the dosage, severity of the disease and the person's life-style needs.

- IF AT ALL IT IS REQUIRED, and as recommended by ones medical consultant, the protein intake may be reduced. This however, is in very rare cases as protein intake is essential to the body. To prevent weight loss at such times, the intake of carbohydrates should be increased.

The ideal ration of protein (P) to carbohydrates (CHO) is 1:5. If this is not helping the patient maintain optimal body weight, the ration may be increased to 1:6 and 1:7. A few examples of how one can incorporate the 1:5 P: CHO ratios are provided in the table below:

PROTEIN	CARBOHYDRATES
1 vati dal / sambhar	¾ chapatti OR ¾ vati rice/ pulao
1 vati curd	½ chapatti OR ½ vati rice
1 cup milk	1 khakhra OR ½ vati poha/ upma
1 whole egg	1½ chapatti OR 1½ vati upma
1 egg white	¾ chapatti OR ¾ vati rice/ upma/ poha
100 gm fish	3 chapatti + 1 vati rice + 1 vati vegetables
100 gm chicken	4 chapatti + 1 vati rice + 2 vati vegetables
40 gm paneer	1½ chapatti OR 1½ vati rice

2) MANAGING WEIGHT

- People suffering from PD may experience weight fluctuations either due to side – effects of the medications, or as a secondary symptom of the disease itself, or due to reduced/ lack of movement caused by rigidity and imbalance. In such cases, the person may go on a calorie – controlled balanced diet as recommended by a registered dietician.
- However, most often the problem with people with PD is weight loss, which may be due to loss of appetite, swallowing difficulties, difficulty in using utensils, increased energy depletion (in trying to cope with symptoms). In such cases they should be encouraged to take in more calories in the following ways:
 - Give small and frequent meals, instead of bulky meals.
 - Give favorite foods and try to modify them according to nutritional requirement.
 - High calorie foods like peanut butter; biscuits/desserts and milkshakes can help to increase weight, and may be given in appropriate quantities.

3) CONSTIPATION

Another very common symptom faced by people suffering from PD is constipation, which may be defined as bowel emptying less than thrice a week, or uneasy feeling even after bowel emptying. Constipation in PD is a problem because the condition reduces the action of muscles in the bowel. However, it can be easily managed with a natural diet. If constipation becomes a more serious problem, then medical consultation may be necessary. A few dietary tips to prevent or reduce constipation are provided below:

- Increase intake of a fiber – rich diet. Foods containing fiber are –
 - Whole – grain bread and cereal
 - Thoroughly washed raw fruits (with skin, if edible), especially prune, pear, peach, papayas, unstrained fruit juices
 - Dry fruits. (Avoid them if you also have heartburns).
 - Vegetables especially leafy vegetables like cabbage, cauliflower, broccoli, and celery.
 - Lentils and split peas.
 - Bran (can be added to meals).
 - Drink plenty of water.
 - Drink hot fluids. However, avoid tea and coffee as they dehydrate the body thereby worsening constipation.
 - Regularize meal timings.

4) SWALLOWING AND CHEWING PROBLEMS

If a person with PD has swallowing or chewing problems as a secondary symptom of the disease itself, then one can aid oneself by following the dietary tips given below:

Consumption of the following foods may minimize chewing, and facilitate swallowing:

- i. Upma/ Chopped, Mashed or Pureed Foods
- ii. Porridge or Gruel
- iii. Poha/ Khichdi/ Dhokla/ Idli/ cutlet
- iv. Soups/ Kanji
- v. Buttermilk/ Lassi
- vi. Milkshakes/ Juices
- vii. Egg custard/ Pudding/ Kheer
- viii. Rice preparation with raita
- ix.

5) GASTRO ESOPHAGEAL REFLUX DISEASE (GERD)

Gastro esophageal reflux disease, commonly known as heartburn is another common problem among PD patients, due to fluctuations in the body mechanisms. Following the subsequent tips can prevent this:

- Give small and frequent meals, avoiding bulky meals.
- Use cumin (jeera), coriander, curry leaves, lemon juice, asafetida (hing). Avoid chilly, pepper, ginger, garlic, and garam masala.
- Avoid tobacco, alcohol and carbonated beverages and peppermint.
- Avoid extreme hot or cold foods.
- Avoid nuts and dry fruits.
- Use boiling, steaming baking or roasting instead of fried foods, which can be spicy too.
- Drink lots of water.
- Tea and coffee limited to not more than 2 cups per day.
- Avoid smoking.
- Do not sleep immediately after meals.

FLUID INTAKE AND PD

Water is the most important nutrient required for a balanced diet and healthy functioning of the body. Drinking plenty of water is particularly important for PD patients because of the secondary symptoms of constipation and dry mouth from which PD patients suffer.

Taking frequent sips of water, or sucking ice chips helps in lubricating the mouth. Constipation is generally aided by the intakes of fluid, and so is it in PD.

However, when one is not used to drinking too much water, they should slowly increase the water intake by increasing half a glass of water everyday till the total

intake is 6 – 8 glasses. Initially there may be water retention, which may cause bloating, but eventually the body will adjust and maintain optimal hydration.

Thus having covered the basic points one needs to keep in mind to follow a balanced diet and an ensuing healthy functioning. Provided next is a ‘Sample Menu Plan’ that can be used by a PD patient, or altered according to individual needs, of course in consultation with ones dietician.

SAMPLE MENU PLAN

TIME/ MEAL	MENU	NUTRITIONAL VALUES
7.00 a.m. DRUG		
8.00 a.m. BREAKFAST	1 cup tea/coffee with sugar + Upma/ Vermicelli/ Rawa/ Poha/ Sheera/ 2 Idlis/ 2 Sada Dosa/ 1 Uttapam + 2 egg white omellete with 1 chapatti/ 2 khakhras with vegetable/ Corn flakes/ Oat flakes/ Wheat flakes/ Muesli with milk.	12 gm Protein 60 gm CHO
10.30 a.m.	Fruit	
12.00 p.m. DRUG		
1.00 p.m. LUNCH	1 vati Jeera rice/ Pulao/ Khichdi/ Plain rice + 1 Roti/ 2 Chapatti/ 1 Paratha + 1 vati Dal/ Sambhar + 1 vati Vegetable	12.5 gm Protein 64 gm CHO
4.30 p.m. SNACKS	Lemon tea/ Black tea/ Black coffee + Fruit juice/ Whole fruit + Popcorn/ Kurmura/ Sukha bhel + Upma/ Poha/ Gavan/ Rice Dosa	2 gm Protein 10 gm CHO
6.30 p.m. DRUG		
7.30 p.m. DINNER	4 small Chapatti/ 2 Roti/ 1 Paratha + 1 vati Rice/ Khichdi/ Lemon Rice + 1 vati Dal/ Sambhar/ Kadhi + 1 vati Usal/ Sprout veg/ Sprout salad + 1 vati Vegetable	(Dinner + 9.00 p.m. snack): 24 gm Protein 120 gm CHO
9.00 p.m.	1 glass Buttermilk/ ½ glass Lassi/ 1 glass milk OR Kheer/ Sheera/ Poha and milk	

Drug Therapy

A Guide to the medication in PD

In collaboration with:
European Parkinson's Disease Association
Parkinson's New Zealand
Dr. Jimmy Lalkaka.



PARKINSON'S DISEASE AND MOVEMENT DISORDER SOCIETY.



A GUIDE TO PARKINSON'S MEDICATIONS

This guide has been produced to provide general information about medications for people with Parkinson's disease (PD), and to detail information about each drug. It is important to bear in mind when referring to the guide that no two people with Parkinson's are exactly the same, and each will have a different combination of symptoms and medication.

The drugs mentioned in this guide and some of the information related to them may change from time to time.

BALANCING YOUR MEDICATION

The main aim of drug treatment in Parkinson's is; to increase the level of dopamine that reaches the brain, stimulate the parts of the brain where dopamine works, or block the action of other chemicals that affect dopamine, such as acetylcholine.

- You will need to work with your doctor to find the right balance of medications to effectively manage your symptoms.
- Drug treatment in Parkinson's is prescribed to suit the individual, both in terms of the dosage and the times the drugs are taken.
- A combination of different medications is often required to provide the most effective symptom control.
- Treatment is generally started with low doses of a drug; this dose is then gradually increased until the required control over the symptoms is achieved. This gradual introduction helps avoid side effects.
- The dose and timing of medications may need to be adjusted over time as your symptoms change (or side effects occur). Accordingly, your doctor will probably want to check your response to the medication.

GETTING THE BEST OUT OF YOUR TREATMENT

Whatever the medication you are taking, it is important to understand:

- How many or how much of your medication you should take.
- Under what circumstances your medication should be taken, for e.g. before, with or after food.
- The importance of taking medication at a regular time recommended by your doctor.
- What other medications you should not combine with your current medication.

- All medications have possible side effects. Most people will not experience these to any great extent. However, if side effects become troublesome, please consult your doctor.
- You should not suddenly stop your medication without consulting your doctor.

Try to avoid starting a new medication when you will not have access to your doctor or other healthcare professional, such as the weekend or public holidays. Always ensure that you have adequate supplies of your medication available.

Your doctor is the best person to advise you on the appropriate drug treatment and to give you further information.

LEVODOPA

Levodopa is converted to dopamine in the body, which then replenishes the deficiency of dopamine in the brain. Levodopa is highly effective in controlling most symptoms of Parkinson's. More than 30 years after its discovery it remains the cornerstone of Parkinson's disease therapy, and a large majority of patients receive levodopa therapy.

Many people find levodopa treatment very effective, but after long-term use its effectiveness may decrease, thus requiring the dosage to be increased. That and the development of involuntary movements (dyskinesias) is why some doctors delay treatment with levodopa for some time.

Levodopa- Carbidopa; like- Syndopa, Sinemet, Tidomet, LCD, & Madopar (levodopa+ benserazide).

Possible side effects;

If at all side effects occur, nausea and vomiting are the most common.

Dizziness, lightheadedness may occur from a lowering of blood pressure.

Dry mouth, headache or constipation may occur

Consult your doctor if any of the above side effects occur or you experience any of the following;

Uncontrolled body movements (dyskinesias)

A fast heartbeat

Any unusual behavior or mood changes.

Controlled release preparations are recognized by the letters HBS or CR after the drug name. These preparations release the drug over a four to six hour period and may result in more even levels of levodopa in the blood. With controlled release preparations the time

between the doses can be prolonged by 30% to 50%. They may be used when a person with Parkinson's is experiencing wearing off of the dose of the standard levodopa. They can also be taken before going to bed to reduce stiffness and immobility during the night.

The Role of Protein:

In some people protein (found in foods such as meat, fish, eggs, cheese, nuts and pulses such as lentils and beans) seems to interfere with the effectiveness of their levodopa medication. For them, the protein can interfere with the absorption of levodopa from the stomach, since both levodopa and proteins are made of amino acids. This may result in less of the drug reaching the brain. Thus the efficacy of the drug is reduced if taken after or with a protein-rich diet.

In such a case, it would be more beneficial to keep a gap between taking the levodopa and meals. (Ideally, with a carbohydrate food like a biscuit or cracker). If this doesn't help, one may try a protein redistribution diet, where most of the daily protein is taken in the evening. This can help the levodopa treatment to be more effective in the day-time, when you are likely to need it more. However, as protein is essential for a healthy diet, you should not reduce the overall amount of protein you consume.

It is important that any changes to your diet are undertaken only after a full discussion with your doctor or dietician.

DOPAMINE AGONISTS

Dopamine agonists stimulate the dopamine receptors rather than replacing it in the way that levodopa does.

Dopamine Agonists include- Bromocriptine (like- Proctinal & Parlodel), Carbergoline (like- Carberlin, Cabgol), Ropinirole (like- Requip, Ropark, Ropiro), Pramipexole (like- Pramipex, Pramirrol), Lisuride (Dopergin)

Dopamine agonists mimic the signal from dopamine that is lost in Parkinson's disease. The drugs are usually started at a low dose and increased slowly to reduce any possible side effects.

Several clinical studies have shown that dopamine agonists can be effective treatments for several years when used alone and the likelihood of developing dyskinesias is reduced while people remain on a dopamine agonist alone or in combination with a low dose of levodopa.

Dopamine agonists are best taken with meals.

Possible side effects;

Nausea and vomiting. Confusion and hallucinations. Dizziness or lightheadedness. Dry mouth.

Drowsiness can also be a side effect of dopamine agonists and can sometimes be severe. Accordingly, those experiencing these should take the necessary precautions while driving, operating complex machinery, or participating in any potentially dangerous activity.

Some people with Parkinson's continue to experience sudden fluctuations in their symptoms in spite of all efforts to adjust their medication. In these cases, injections of Apomorphine maybe used between doses of their usual medication.

As Apomorphine can only be given by injection, people with Parkinson's and their carers have to be able to cope with this, also assessment and training is required.

Many people self- inject intermittently, with a syringe or a pre-loaded metering device, but some may need a more continuous supply of Apomorphine and so may require an infusion pump. This portable battery-driven syringe pump works by the insertion of a needle under the skin of the outside of the thighs, or into the abdomen (below the navel).

Apomorphine causes severe nausea & vomiting, so an antinauseant like domperidone is prescribed before and during the introduction of Apomorphine and longer.

Apomorphine may initially make dyskinesias worse. Soreness can develop at the injection site and if this occurs, you should seek the advice of your doctor.

AMANTADINE

Amantadine does several different things, but its main beneficial effect may be to promote the release of dopamine and to allow it to stay longer at its site of action. Amantadine can be used as a monotherapy in the early stages of PD, especially in younger people. If stopped suddenly it can cause a worsening of PD. It may sometimes help reduce dyskinesias. Amantadine may have a stimulatory effect and can help some people with tiredness.

Common Amantadine preparations include-Symmetrel, Amantrel

Common side effects include;

Nausea, insomnia, dizziness or lightheadedness, swelling of the ankles, a mottled appearance on the skin of the lower leg. It may sometimes cause confusion or hallucinations in older people. Contact your doctor if any of the above side effects persist or become troublesome.

#ANTICHOLINERGICS

These are older drugs, less commonly prescribed these days, which can have a mild effect on the symptoms of Parkinson's (mainly tremor) by blocking the action of the chemical messenger acetylcholine. Anticholinergics are often prescribed alone, or they may be used in conjunction with levodopa or other medications.

Common Anticholinergic preparations include; Pacitane, Kemadrine, Bexol

Anticholinergics can be useful for younger people in the early stages of Parkinson's when symptoms are mild. They tend to improve tremor more than slowness and stiffness. Anticholinergics may also be used to reduce saliva production when drooling is a problem.

These drugs are not prescribed to older people with Parkinson's because there is an increased risk of confusion as well as memory loss, and urinary hesitancy in males.

Possible side effects;

Confusion, memory loss, dry mouth, nausea, constipation, and blurring of vision can occur. Consult your doctor if any side effects persist or become troublesome, or if you experience any of the following:

- Severe eye pain
- Seeing or hearing difficulties
- A fast or irregular heartbeat.

If you have glaucoma you should consult your doctor before taking this drug.

MONOAMINE- OXIDASE TYPE B (MAO-B) INHIBITORS

Monoamine oxidase type B inhibitors (MAO-B Inhibitors) slow the dopamine breakdown in the brain. They are used to make the dose of levodopa medication last longer or reduce the amount required.

MAO-B Inhibitors include Selegiline (like- Selgin, Eldepryl)

This drug can be prescribed on its own or in addition to levodopa. Selegiline is often prescribed as a single dose to be taken in the morning rather than in the evening when it might interfere with sleep.

Selegiline should be used with caution when used in combination with antidepressants and with cold and cough preparations containing dextromethorphan.

Possible side effects;

By itself, Selegiline has few side effects; dry mouth, sleeping disorders, hallucinations, and postural hypotension are the most commonly reported.

COMT INHIBITORS

These new medications work by blocking an enzyme called catechol-O-methyl transferase (COMT) which breaks down levodopa. As a result they slow the destruction of levodopa in the body allowing more levodopa to pass into the brain to be converted into dopamine.

COMT Inhibitors include; Entacapone (Entacom, Adcapone, Comtan), Tolcapone (Tasmar)

These drugs are particularly effective in people who are experiencing on-off fluctuations. When used with levodopa, they can reduce the daily off time and increase the on time. In many cases, the levodopa dose and dosing frequency can also be reduced.

Be aware that other drugs, for Parkinson's or other conditions, can affect the action of Entacapone and Tolcapone. Most Parkinson's drugs can be taken with COMT inhibitors, except Apomorphine.

Please note: Regular blood tests to monitor liver function are necessary when taking Tolcapone.

Possible side effects;

Dyskinesias, nausea and vomiting, sleep problems. Constipation or diarrhea. Urine can become discolored due to the substances used in the drugs, but this discolouration is harmless.

An increase in side effects after starting a COMT inhibitor should be discussed with the doctor, reducing the levodopa dose can often help in this situation.

COMT Inhibitors are also available in combination with Levodopa- Carbidopa. (These include preparations like; Entacom plus, Syncapone etc.)

#NON- PARKINSON'S DRUGS COMMONLY USED

= Antidepressants=

Research has shown that depression is a common Parkinson's symptom caused by a chemical imbalance in the brain. It is sometimes difficult to distinguish depression from some of the symptoms of Parkinson's; this is why it is all important to discuss all your symptoms with your doctor.

For some people adjustments to their medications may improve their depression, or counseling may help. Antidepressants may also be prescribed to correct any chemical imbalance. Some will be more suitable than others for people with Parkinson's.

There are several types of antidepressants such as Tricyclics, SSRI's, and MAOIs.

Tricyclics

Tricyclics have a sedating effect and so may be good for those who are agitated. They can sometimes help those with drooling, loss of appetite and night- time incontinence.
--

Selective Serotonin Re-uptake Inhibitors (SSRIs)
--

SSRI's are drugs that specifically target the neurotransmitter serotonin. They are believed to have an alerting effect, and may counteract the sedative component of traditional anti-Parkinson's medications.
--

Other antidepressant drugs like, Moclobemide (Apo-Moclobemide, Autorix), Venlafaxine (Efexor), Miiratzapine (Remeron) are the newer anti deppressants and are sometimes prescribed.

Please note: All antidepressant medications have possible side effects. They should be taken only under doctor's consultation.

= Cognitive Enhancers=

Memory loss can be experienced by some people with Parkinson's. For people concerned about memory loss cognitive enhancing drugs commonly prescribed for Alzheimer's such as Donepezil (these include; Aricep, Donep, Donecept), Rivastigmine (these include; Exelon or Rivamer) and Galantamine (these include; Reminyl, Galamer etc) work by boosting existing supplies of acetylcholine. However these drugs are usually available at high costs.

= Drugs for Hallucinations=

Some people with Parkinson's experience hallucinations when they may see, hear, feel, smell or taste something which in reality does not exist.

Sometimes hallucinations occur when an adjustment has been made to the dose of a particular Parkinson's drug or when a new drug is added to a combination that the person is already taking. They may also occur as a result of infection or other illness. On other occasions it seems that the hallucinations occur spontaneously without any immediate cause.

Sometimes, lowering the levels of levodopa may help alleviate symptoms. If this is not successful, neuroleptic or antipsychotic drugs maybe prescribed. Newer antipsychotic drugs prescribed by a specialist to prevent hallucinations include Quetiapine (such as, Qutipin, Qutan etc.) and Clozapine.

BEFORE SURGERY

If you need or are scheduled for any type of surgery, you **MUST** talk to your doctor and anesthetist, before hand, about the medications you are taking, the dosage and the timing of them.

Caring for the Carers

A note for our caregiver's

"Constant reassurance that my loved ones are supportive, patient, caring, understanding, and loving is, I believe, my greatest asset and most secure source of happiness." Dwight C. McGoon, M.D., a Mayo Clinic surgeon with Parkinson's Disease.

We acknowledge the contribution of:

Jyoti Ghanshani
(Clinical Psychologist)



PARKINSON'S DISEASE AND MOVEMENT DISORDER SOCIETY.



For a patient with Parkinson's, a caregiver is indispensable. A caregiver is not only responsible for providing assistance in the daily care activities, but is also a constant support and companion for the patient. Just as the care of the patient is important, the care and well being of the caregiver too is, imperative.

While speaking to a caregiver or any member of the patient's family, it becomes easily apparent that Parkinson's is a large part of their day, everyday. This begins from the very moment that the patient and his/her family begin to note signs and difficulties and seek advice for it.

We realize that, just as much as for the patient, it is not easy for the caregiver (usually the person in the family that is closest to the patient) to accept the diagnosis of an illness, more so one that you are just beginning to learn about. The reactions of the patient and caregiver usually mirror each other.

Questions and a wave of emotions flood your mind. Crowding these questions, feelings and confusion are silent pleas for help. The prospect of what lies ahead seems so frightening and there is such little direction for help!

And so, we acquire the role of 'the responsible one' 'the protector' and most importantly the "one to be strong and provide strength".

"Caring for myself" is an important consideration for all caregivers! We could offer some suggestions for the same.

- = pursue and develop your interests (creative pursuits, reading, writing, spiritual interests)
- = create a social network (friends, family, outings etc)
- = attend to your fitness and health (yoga, exercise, diet, specific ailments: diabetes etc)
- = Understand that it is acceptable to have mixed feelings:
- = Understand that you cannot create or cure illness, but can help relieve discomfort.
- = Talk about it: Do not keep your emotions inside—develop a support system
- = Set your own goals: You should decide what you can and cannot do. Do not let doctors or other family members decide for you what you should be doing.
- = Share responsibility. It is ok to ask for help and the variety in company is welcomed by patients too.
- = Be proactive, take initiative and get involved in the activities. Company is a great motivator.
- = get involved in program to create awareness about the condition. This helps you meet more people, share more perspectives.

What is caregiver burnout and what can you do to avoid it?

Over a sustained period of time, the emotional, physical, and financial implications of caring for a patient with Pd may begin to affect the caregiver, especially if they are not shared or addressed from time to time. Caregivers may feel overwhelmed, exhausted,

frustrated, resentful, and guilty. Thus leading to a burn out. Some of the signs of burn out include;

Physical signs like- Headaches, Chronic back pain, Other muscle tensions, Sleep deprivation, Digestive problems, Heartburn etc. And,

Emotional signs like- Increased anger, Increased anxiety, Fatigue, Emotional exhaustion, Sadness in mood or Depression, Isolation or Withdrawal, Increased use of nicotine/alcohol/drugs.

We have a cultural advantage, in that the care is easily shared within family and help and support are easily available. Nonetheless, signs such as these should not be ignored. Moreover, we must also discuss our feeling and concerns and give vent to them. This sharing is most beneficial for the caregiver and the patient.

New Directions

Directions towards helping everyday living with PD

This section includes:

Creating Support; Support Groups

Yoga & Parkinsons

Young Onset Parkinson's

Reaching Out



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CREATING SUPPORT

What is a support group? Why join a support group?

A support group is an informal gathering of people who share similar experiences, situations or problems. By meeting together, Parkinson's Support Group members can offer each other emotional and practical support.

What do we do at a support group meeting?

- Group discussions
- Share experiences and practical tips on living with Parkinson's
- Learn about Parkinson's its problems and treatment
- Lectures and demonstrations that stress the multidisciplinary approach to Parkinson's. Topics include Physiotherapy, Occupational therapy, Speech therapy, Diet and Nutrition, Counseling, yoga etc.
- Organize programs based on the needs expressed by the members. Some of the programs and activities organized are 'Yoga for Parkinson's', 'Art therapy', 'Physiotherapy sessions', 'Educational and Cognitive training sessions.
- Share a cup of coffee or tea.

Besides helping you realize that you are not alone, Parkinson's Support Groups offer you a number of services and benefits:

- They give you a chance to share your feelings and hear the experience of others
- They help you to understand and be understood by others in similar circumstances
- They encourage the growth of knowledge. By knowing more about Parkinson's through the experience of others and through professional resources you discover new ways of dealing with your own symptoms and problems.
- They help renew your sense of hope in dealing with changes in your life style
- They give you a chance to make new friends and to break down feelings of isolation.

YOGA AND PARKINSON'S DISEASE

Dr Rajvi Mehta

Introduction: Yoga is an ancient Indian Science, which has been used for centuries to give physical and physiological health, mental peace, emotional equanimity and intellectual clarity to the practitioners. It involves the performance of various asanas (yogic postures) and pranayama (modulation of breath) to achieve its goal. In the last few decades, its popularity has been on the rise and people are now realizing its therapeutic benefits. Yogacharya BKS Iyengar, one of the world's leading authorities on yoga has evolved various modulations of the classical yogic postures to aid individuals to attain benefit from their practice for specific medical problems. He has also invented many "props" which make it possible for one and all, including those with major physical and physiological limitations, to perform these yogic postures and attain benefit from their practice.

Practice of yoga can help patients suffering from Parkinson's to control the disease and endure the disease. A research study was carried out by the Parkinson Disease and Movement Disorder Society in collaboration with the Light on Yoga Research Trust Mumbai.

The research study: The objective of the study was to determine the efficacy of yoga in altering the quality of life of patients with Parkinson's disease. Two groups of patients matched with reference to age, gender and stage of disease were selected. One group of patients underwent "yoga therapy" for three months. They were evaluated using various non-invasive tests before and after the study period.

The patients were made to practice specific yogasanas for 1 ½ hours daily for a period of 10 days spread over 2 weeks (two sessions from Monday to Friday). The classes were held in the afternoons at a time mutually convenient to the patients and the yoga teachers. All the patients were taught simultaneously at the Iyengar Yogashraya.

Following the initial two weeks, the patients were asked to attend classes once a week for another 8 weeks.

The yoga classes: The patients were made to perform various yoga postures (asanas) with the help of props. These asanas would be standing, supine, sitting or inverted and be done under the supervision of trained teachers of "Iyengar yoga". The asana-s were done in such a manner that even the patients with very limited flexibility or mobility were trained to perform them.

The results of the study: There was a significant improvement in the group of individuals who underwent training in the yoga classes as compared with the control

group. There was an improvement in their mobility, flexibility, emotional state as well as their quality of life. This was reported not only by the patients but was detected in the different tests that the patients were subjected to.

The researchers are thankful to the participants of the study.

Subsequent to the findings of these studies, regular sessions are being conducted at Iyengar Yogashraya to facilitate patients with PD cope with their disorder and gradually alleviate their symptoms.

Contact details for further information and to register for the session

Iyengar Yogashraya, 126 Senapati Bapat Marg, (opp. Kamla and Empire Mills) Lower Parel, Mumbai 400 013. Phone 2494 8416.

General Instructions for patients

- The patients should preferably wear t-shirts and shorts or tights and track pants.
- All the props required such as blankets etc. would be provided at the venue. The patients need not carry anything.
- The patients should have their lunch at least 4 hours before the class. However, they can have something to drink or a light snack an hour before the class. They can eat half an hour after the class.
- The patients should continue with whatever medications that they have been advised by their physicians. They should preferably not change any medication during the course of the study.
- They should inform the teachers at Iyengar Yogashraya, in case they have any specific problems other than those related to Parkinson's on any given day. For example, cold cough, indigestion etc.

YOUNG ONSET PARKINSON'S

Shibani Devare

Though Parkinson's Disease is traditionally been thought of as a disease of old age, various studies show people being diagnosed with Parkinson's at an early age.

The impact of a Parkinson's diagnosis on a younger person may be most significant in regard to the psychological and emotional effects that they experience. As the condition begins at an earlier age, diagnosis comes at a time when many younger people are still leading very active lives, perhaps developing a chosen career, raising a family or thinking about starting one!

Period after diagnosis can often be a particularly difficult time. This can lead to experiencing different and conflicting emotions. Acknowledging and accepting these effects is an on-going process and for most people will take some time. Although it may not always be easy, developing as positive an attitude as possible towards their Parkinson's can make an enormous difference to how they live their lives.

Accepting the diagnosis is often the first step towards finding your own way of coping with Parkinson's. Research indicates talking to someone about your feelings and situation helps in acknowledging the emotional conflict. If you are finding it difficult to cope, it is particularly important to find some support for yourself before the situation reaches crisis point. Who you talk to depends on your personal circumstances, the difficulties you have and who you feel most comfortable with. You may find it helpful to talk to other people with Parkinson's.

Keeping this in mind PDMDS plans to start a special interest support group specifically for people diagnosed with PD before the age of 60.

The PDMDS plans to conduct and organize support group meetings for early onset patients (age group 25-60) in Mumbai. Since most of you are working, we are planning to organize a convenient time and place, suitable for your attendance. Additionally, we plan to develop a bulletin board on the PDMDS website. The website portal will be useful in sharing your experiences and also help in keeping the identity anonymous. If you would be interested in participating please contact us on the following address:

Your details can be sent to us by email on pdmds.india@gmail.com

OR

Contact: Ms.Shibani 996-777-4944

Please feel free to contact us for any further information.

REACHING OUT

Jyoti Ghanshani

We understand that Parkinson's disease is both Progressive and multidimensional in its character. With time as the condition progresses we may find that our symptoms debilitate our everyday living significantly. It may affect our independence in our self care, restrict our mobility, as well as affect our other symptoms. Additionally, we find that it may also affect our emotional well-being, our morale and the way in which we relate to those that care for us.

At such times reaching out to professionals, seeking their advice is important. However we may experience some restrictions with regards to venturing outside of the comfortable space of our home or in some cases, the extent of the physical disability may not allow us to leave our homes. Thereby coming in the way of availing such help.

Bearing this in mind, PDMDS has devised an outreach program. This program is intended to address the needs of patients with restricted mobility, in an attempt to improve their quality of life.

Representatives from PDMDS will come to your house to meet you and understand your difficulties; including your physical, psychological, social and emotional needs as well as those of your caregivers. Accordingly attempts will be made to make the appropriate therapy, rehabilitation, counseling or social care services available to you.

For those who are interested in participating in this program, please contact us with your details.

For contact or further information:

Call us on: 022-22007667 or
996-777-4944

Email us at: pdmds.india@gmail.com

Write to us at: 6, Jasville,
New Marine Lines,
Opposite Liberty Cinema,
Mumbai-20

Taking Control

Hints and strategies for everyday living with PD

This section includes:

Do's and Don't for medications in everyday life

Record for motor fluctuations

Record for medications

Psychoeducational strategies

In collaboration with:
European Parkinson's Disease Association
Parkinson's New Zealand
Jyoti Ghanshani (Clinical Psychologist)



PARKINSON'S DISEASE AND MOVEMENT DISORDER SOCIETY.



DOS AND DONT'S for Medication in Everyday life

- DO ask your doctor to explain something again if you do not understand.
- DO report the effects of medication, good or bad, to your doctor. It is useful to make some notes in advance of your appointment so that nothing is overlooked.
- DO keep a diary or chart particularly when starting a new drug or when adjusting your doses. Record the doses and timing of your drugs, the duration of your on and off period or dyskinesias and anything unusual you may experience. This can be extremely helpful for the doctor when tailoring your new drug regime. If you have difficulty writing, ask someone to fill in any information for you. to help with recording your medication and on-off period you may use the tables given in this section of the guide.
- DO take a forgotten dose as soon as you remember, provided this does not result in a taking a double dose. If that should be the case, omit the forgotten dose.
- DO seek advise from your doctor if you have concerns about any aspect of your life which maybe affected by Parkinson's or your Parkinson's medication, such as traveling, physical intimacy etc.
- DO remember that unexpected dizziness maybe a symptom of low blood pressure. If you experience this, you are advised to have your blood pressure checked in both lying and standing positions.
- DO consult with your doctor before making changes to your treatment.
- DO take your drugs at regular time recommended by your doctor. Taking medication on time every time ensures you get the maximum effectiveness and benefit from Parkinson's drugs.
- DON'T assume that your treatment, dose, or the timing of your medication, should be the same as that of other people with Parkinson's. Should you go into hospital or respite care, it is important that the doctors, nurses or careers know your current medication regime and the time of day you take each medication. DO keep all of your Parkinson's information together in a folder for this purpose.
- DON'T assume that you will experience serious side effects- most people won't. However, if there is anything of concern, report it your doctor.
- DON'T suddenly make big changes to your dose. Rapid changes in dose can provoke side effects. Your doctor is likely to suggest that you experiment with timings to find the regime that suits you, while maintaining the daily doses that has been suggested. And certainly, DON'T suddenly stop any of your Parkinson's medications without first consulting your doctor.

WEARING OFF RECORD

To help follow your symptoms and response to treatment, record daily observations in this record (see examples of some symptoms below). This record is extremely useful when taken along to medical appointments, allowing the doctor to follow how the medication is working and as a result, to prescribe therapies most appropriate and effective for your particular needs.

The record attached is a prototype and maybe photocopied as more pages maybe required.

Date: _____

	Time spent ON or OFF	Dyskinesias Experienced? (yes/no)	Symptoms Please list	Medications taken (please list, including dose)
Morning	Mostly On	No	Sickness, Dry mouth (after food), difficulty moving.	Three doses
Afternoon	1 hour OFF	No	Dizziness, shaking of hands started before the next dose.	Two doses
Evening	1 hour OFF	Yes	Tiredness, aching legs- more than usual	Two doses

Date: _____

	Time spent ON or OFF	Dyskinesias Experienced? (yes/no)	Symptoms Please list	Medications taken (please list, including dose)
Morning				
Afternoon				
Evening				

Date: _____

	Time spent ON or OFF	Dyskinesias Experienced? (yes/no)	Symptoms Please list	Medications taken (please list, including dose)
Morning				
Afternoon				
Evening				

PSYCHO-EDUCATIONAL STRATEGIES

When we experience a difficulty with our mental faculty, all chances are that we ourselves will be the first to notice it. When a difficulty disturbs our daily functioning 'a little' we give it 'little' thought and find ways around it, however some experiences may require further thought. To ascertain whether or not a particular difficulty is pointing towards a significant loss try to objectively judge the frequency of the episodes and the quality of the difficulty. Some questions that may help you introspect;

-Is there any new change in our mental functioning such as difficulty in paying attention, finding words, making decisions, telling time, remembering people?

- How often does the memory trouble occur? Daily?

- What is being forgotten? Is there trouble recalling recent events? Are simple tasks hard to organize and perform? Does one get lost in familiar places?

-Are there any new emotional symptoms such as a change in emotional state or personality, such as irritability or suspiciousness, that are unlike your usual self? Is there sadness or loss of interest in usual activities?

There's little doubt that the more you use your mind, the better it gets!! And as your mind improves, so your thoughts become clearer, more creative and your level of energy and motivation will go up in everything you do.

Doing puzzles, playing board games, reading regularly help build the minds strength and protect it to a large extent from the development of cognitive difficulties. There are other novel activities that you could also try or develop on your own!

2-minute Mind Workout;

Objective:

Sharpens focus and attention

Description:

Use a clock with a second hand and place it directly in front of the TV. Switch on the TV and try to focus your attention on the movement of the second hand without allowing the TV to distract you. Start small; go from focusing on the seconds hand for half a minute right upto two whole minutes.

Reward yourself each time ☺!

#Backward Spelling;

Objective:

Develops thought clarity and also sharpens verbal ability.

Description:

Randomly select some four-letterd, five- letterd and six-letterd words. You can start with a set of one each (3 words) going upto a set of five each (15 words). Begin with the four-

lettered words. Glance at the word, then turn away and spell it backwards aloud! Do this for each word in the set.

You can also enlist a partner to compete with.

Repeating Digits;

Objective:

Helps develop attention, acuity and immediate memory.

Description: Enlist the help of a partner and develop a set of number sequences starting from a pair of 2 digits upto 6 or 7 digit sequences. List out 2 sequences of each length, ie; 2 two digit sequences, 2 three digit sequences etc. Now read out the sequence to the beat of a second and have your partner repeat the numbers in the exact sequence. Try an alternate of having to repeat the sequence in reverse order!! See how far up you go both ways.

Brain Gym;

Objective:

This exercises numerical analysis, auditory attention, motor coordination and planning, all at once.

Description:

Recite numbers from 1-100.

For every number divisible by 3-raise your right hand

For every number divisible by 4-raise your left hand

For every number divisible by 3 & 4-clap your hands

As a variation, try stamping your feet for every number divisible by five.

#Virtual Treasure Hunt;

Objective:

Exercises visual scanning, observation, memory and perceptual recognition skills.

Description:

Use a picture that is full of objects. These can be found in magazines or even picture books. Study it for a minute and put it away. List as many objects as you can remember.

As a variation, try studying a complex coloured pattern and try to recall as many colours as possible.

Strength in Association;

Objective:

Supports memorizing several items or tasks by creating multiple associations.

Description:

Using a list of tasks or items, create mental images relating each item to something. These images could form part of a bizarre story or could be placed spatially along a familiar path. The more ridiculous the association the more likely it is to remain in your mind. The association is even strengthened by incorporating different senses into it like, smell, taste, feel etc.

Now recreate your imagery to recall all your information.

- ✓ Some other strategies that maybe helpful for specific difficulties are;

Taking in New Information

- Keep information simple and repeat it frequently
- Break new activities down into small stages; “ mini activities”
- Put a routine in place. This helps create a certainty and security, and makes it easier for us to know by sequence the things that happen through the day. A routine also helps establish orientation.
- Allot a place for things and try to keep your things there enabling us to locate them easily. Example: a key ring by the door.

Avoid Unnecessary Stress

If a person is tired, unwell, anxious or depressed, they will find it even more difficult to remember things! Memory problems will also become more apparent if one tries to do more than one thing at a time, or if one is distracted by noise or bustle.

Most importantly therefore, avoid any pressure! It is easier to remember, if you do not feel like you're in the spot light for not remembering.

Use verbal cues to help jog your memory, and in this elicit the help of those around you.

#Make the most of Memory Aids

Memory aids such as lists, diaries, organizers, post-its, alarms and clear, written instructions can help jog the person's memory and maybe used for multiple purposes.

#Coping with memories of the distant past

Most people with significant memory difficulties remember the distant past more clearly than recent events. The person may be anxious about forgetting their past – particularly in the early stages of dementia. Try and allow for opportunities to share memories through looking at photographs and souvenirs together. This can jog memory, and may help to restore a sense of calm and coherence. Talking about the past can be enjoyable and may help them retain their sense of who they are.

For caregivers it is important that they try not to contradict. Instead, try to relate to what the person is remembering or feeling. Encourage them to talk about the past and comfort them if they seem sad. Try to give them the chance to express their feelings, and show them that you understand.

Everyone's experience of Parkinson's will be different. Each person will have his or her own way of dealing with the condition-what works for one person will not necessarily work for another. In order to keep this book a handy size, it is not been possible to include every aspect of life with Parkinson's Disease. However, where a subject is not dealt with in detail, comprehensive information can be sought.

We hope that you will find this guide valuable in everyday life and that the combination of tools provided here will help you maintain a full and active life following a diagnosis of Parkinson's Disease.



PARKINSON'S DISEASE AND MOVEMENT DISORDER SOCIETY.

