



movement

News Journal of
Parkinson's Disease and Movement Disorder Society (PDMDS)

Issue 05 | September 2006

PDMDS' ANNUAL PATIENT – CAREGIVER – SEMINAR

The Parkinson's Disease and Movement Disorder Society (PDMDS) held an interactive session entitled "The Management of Parkinson's Disease Including Emerging New Therapies" on 29th April '06 at the S. P. Jain Auditorium, Bombay Hospital.



Dr. Singhal (standing) introducing the panelists (from L to R) Ms.Vania, Dr. P. Wadia, Dr.Sankhla, Dr.Katrak, Dr.N.Mehta, Dr.R.Mehta, & Ms.Sanghi

This day also marked the release of the fourth issue of the PDMDS news journal "Movement" which was distributed, along with informative pamphlets on physiotherapy, disability certificates, and income tax benefits for PD patients & an Education Booklet, to its approximately 200 PD patients & caregivers.

The session began with Mrs. Kavita Shanbhag invoking a beautiful prayer bhajan. Dr. B. S. Singhal, Hon. Secretary of PDMDS in his welcome speech, encouraged those present to actively participate in the proceedings. He made a special mention of the good work being done by Mr. G. S. Kohli as the editor of our newsletter and towards the cause of PD.



An engrossed audience

Dr. Maria Barretto, Coordinator of the PDMDS gave an overview of the activities of the PDMDS in the preceding year. She talked about the support groups, national

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The contents of *movement* aim to provide the maximum possible facts / information but since some information involves areas of personal judgement, their publication does not mean that the PDMDS necessarily endorses them. All contributions are welcome. Essays should be restricted to 750 words, and letters to 200. Your questions too are welcome. Contributions must include your name, address, phone no. and occupation. All materials submitted become the property of PDMDS.

movement

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From the editor's desk



In the last Update I had mentioned that though a 'cure' is not yet in sight, there have been some noteworthy developments, both pharmacological & surgical, in the management of Parkinson's Disease. This includes the availability of a number of drugs that, till recently were not available locally. The 'cure' hopefully will not make us wait too long, but while we do, let me remind you of some important 'dos':



DIET :

Nutrition is the key to leading a near normal life with a chronic ailment. Protein, the virtual muscle builder & therefore ALL important part of nutrition, interferes with the absorption of levodopa when present simultaneously. Patients are therefore advised to avoid having a protein rich diet through the day & compensate by having their full day's protein requirement with the night meal. Patients & caregivers may request for a free copy of 'Parkinson's Disease Food – Guide', a ready reckoner listing some 450 items of everyday edible products, amongst others with their protein content. The values shown are for the edible portion of 100 grams of the food item. A protein content of 12 gms. or above is a 'NO' for day time eating. Also, eat several small meals through the day rather than two or three big ones.

YOGA :

Encouraged by the benefits reported by a number of support groups as also the 'study of the effects of Yoga on Parkinson's Disease', in this Update we bring you a detailed report on the experiences of patients & caregivers. There is no doubt that Yoga, like Tai Chi, Acupressure, Acupuncture, massages & even music can be successfully used by PD patients as complementary therapies to medication, in order to improve their functionality, & thus the quality of their lives. Read the report & you will give 'hope' a good name !

CARE GIVING :

Care giving is a complex task & most often thankless. The patient is not the only one affected by the disease ; his care giver too loses some of the quality of his life,

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Parkinson's Disease and Me

Ronald Rodrigues

This is an attempt to try and explain what it is to have PD. This has been called a designer disease since no two people have the same symptoms. Similarly what I feel today may or may not be the same tomorrow. PD medication for most of us reduces the severity of the symptoms. However as the disease progresses through the middle stage, the side effects start to occur. It is my prayer and hope that in the days to come with newer drugs things will get more pleasurable.

Tremor: I do not experience much tremor. Over the years I have spoken to people whose tremor dominates their lives. They find themselves frustrated at not being able to perform the simple tasks and often avoid social settings for fear of being a source of embarrassment for themselves and those around them.

Rigidity: It is often perceived that PD is painless. This has not been my experience, my hands, legs and back ache, which results in my poor posture. Rigidity also robs me of my true relaxation.

Bradykinesia or slowness of movement: This includes the inability to start a movement, reduced arm swing, a shuffling walk, reduced facial expression, swallowing problems and drooling which is yet another damper on socialization.

Facial masking: When engaging in a conversation with people affected with PD, often an opinion is formed that people with PD are not interested in or even listening to what the other person is saying. This is often interpreted as rudeness, lack of cooperation or even stupidity on the part of the individual with PD.

Hallucinations: I haven't had them and hope never to have them. I experience dystonia as part of the change from 'off to on'. It is another symptom of painless Parkinson's. I feel my feet go rigid and turn into a spasm. I also experience the curling of my feet, especially my toes. It is frustrating for me to live my life during my 'on and 'off' periods. I do my best with my 'offs' and sometimes I do nothing at all with my 'ons' whereas other times I enjoy listening to some old good music or doing some yoga exercises to keep me fit.

Some say you do not die of Parkinson's, you die with it. I say I live with Parkinson's and before I die I intend to live without it.



YOGA FOR PARKINSON'S DISEASE

Several therapies complementary to medication have been tried by PD patients worldwide to improve their quality of life and help them perform day to day functions. These therapies include Tai Chi, Acupuncture, Acupressure, Massage Therapy, Music Therapy, and, our own Indian sage Patanjali's 5000 year – old Yoga.

The PDMDS, along with the Iyengar Yogashraya has been involved in establishing the benefits of Yoga in individuals suffering from PD. Our own PDMDS patient - members underwent a 3 – month Yoga course under the guidance of teachers from the Iyengar Yogashraya at Lower Parel, Mumbai in September 2005. We had encouraging feedback, both from the observers / care-givers and the PD patients.

The observers saw visible improvement in the status of the PD patients. According to Ms. Navaz Irani, Clinical Psychologist, “The changes that I observed in the patients, progressively over the course of three months, was very palpable. As time passed, patients even stopped asking for help while performing the Yogasanas. This wasn't because they just got used to the Yoga routine, but because they were actually appearing more flexible... the improvements went beyond the physical, patients were looking better psychologically and emotionally”. According to Yoga Instructor Ms. Mandira Datta, “I recall most graphically the restfulness and calm when the PD students were in Sarvangasan, as though saying ‘we're home, home within ourselves.’ Mr. Nath who has resumed coming to the Trust classes after a gap of 6 months, walks out of the class peppier, straighter, elated.”

The caretakers of the PD patients had a similar take on this. Observes Mrs. Mehta, wife of a PD patient who participated in the Yoga, “he has started sitting straight, and he also walks much faster now”. Mrs. Nath also feels the same about her husbands' posture, besides observing that he now takes longer steps, and his arm swing has improved. Mrs. B. Ayaz's husband states that, “she feels less stiffness, and has become more active. Her facial expressions can also be seen more now” Mrs. F. Goes' son nods in agreement when she states that she can walk better, and her posture has improved, adding that she seems much happier now. Mr. Visaria says that his wife “curling of the toes has reduced a lot”.

What about the PD patients themselves? Most of them reported to us that they certainly felt an improvement in their condition and their performance of day – to – day activities. Several patients felt that their overall posture had improved; they were in better control of their balance, they were walking better, their stiffness had reduced and they felt an all pervasive sense of well – being. Mrs. Ayaz feels less stressful, while Mr. H. Singh feels that his “anger, behavior and mood is now ok”. Mr. Baker tells us, “I am more mobile, I take initiative... and I feel optimistic, on the whole I have greatly benefited”. Mr. Betrabet reports a general sense of alertness, as well as awareness of when his posture is bad, thus enabling him to make changes to correct it. On similar lines, Mr. J. Joseph also reports being able to concentrate more. Mrs. L. Kavasias says that due to the Yoga program she can now sleep well, while Mr. Mandavia reports a feeling of “freshness”. Mr. Nayak who has had PD for over 16 years lists a lot of changes after yoga. He says, “There is general improvement. I feel more energetic, my back pain has reduced... I can sit on a stool for half an hour, and can get up independently”. Unexpectedly, there have been some “wonder stories” too. While Mr. Joseph has



YOGA FOR PARKINSON'S DISEASE

started driving again, Mr. Mascarenhas has started taking trips back to Goa! Mr. Ubhaykar, who at the end of the Yoga course told us that he was raring to return back to work and go out socially, has done just that.

PDMDS and the Iyengar Yogashraya will be starting Yoga therapy classes for Parkinson's patients at Iyengar Yogashraya itself on 11th September '06 (details provided below). As Mr. P. D'lima, who feels more relaxed after the yoga program, states, "Other Parkinson's patients being there and around you helped in its own way". Therefore, you may at least take a sense of relatedness and attachment, and may be motivated seeing other people like you "perform".

DETAILS OF YOGA PROGRAM

Program Commencement: 11th September, 06.

Program Details: From 11.9.06 daily for a period of 10 days spread over 2 weeks (five sessions a week from Monday to Friday). Following the initial two weeks special classes once a week for another 8 weeks.

Time: 4.00 p.m. – 5.30 p.m.

Venue: Iyengar Yogashraya, 126, Elmac House, Senapati Bapat Marg, Opp. Kamala Mills, Lower Parel, Mumbai.

Tel. No. 24948416

Contact (for further details): Ms. Navaz Irani– 9892149259

FOCUS ON CAREGIVERS - A REPORT FROM PUNE

Mr. & Mrs. Madhusudan Shende

In order to help us understand how the PD community in Pune functions, Mr. Madhusudan Shende, a PD patient himself, along with his wife a caregiver, provided us with some useful inputs. Say Mr. and Mrs. Shende, “It was in the year 2002 that about 50 - 60 PD patients and their caregivers took part in a get-together (organized by Dinanath Hospital) in Pune.” There Mr. Shende met Mr. S. B. Patwardhan, his old classmate and a caregiver to his wife suffering from PD. They both took the initiative to further meetings that were held at Mr. Patwardhans’ house every month. By 2004 they managed to create a data – base of PD patients, who would meet at various places for everyone’s convenience. They also distributed useful literature to the patients. Mr. and Mrs. Shende believe that care – givers and the relationship between a caregiver and a patient are an extremely important part of a PD patients’ life. Therefore following interactions with PD patients and care – givers in Pune support group meetings, they write the following:

“A Caregiver (CG) is a person taking care of someone who is important to him/her. Care giving is an expression of love for someone and has to be a satisfying work on fulltime basis. In India a caregiver feels tied down, lonely, frustrated, and sad. The mobility is low and old age adds to it.. A PD patient (PDP) is normally a Senior Citizen and retired. The caregiver is normally the spouse. Because of economic - social situations many patients as well as the caregivers are not keen on attending meetings or reading literature.”

“The couple, (PDP and his/her spouse) belongs to a generation which is badly hit by sharp-rising costs. Many of them are compelled to stay away from their children, friends and well wishers and hospitals. PD is a progressive disease and medicines need to be increased time and again. Patients from all classes of society feel the brunt of cost on treatment of PD at some stage or the other.”

“Care giving is a difficult work indeed. It involves a composite task of caring and coping, figuring out creative solutions and striving to keep the caregiver’s head cool. A support group can give some relief. The PDP is not the only one affected by the disease, not the only one who has lost the lifestyle formerly shared by both the PDP and CG. They feel that other members of the family don’t help out enough or are critical. The anger builds up and they may be irritated with doctors and other professionals at times in spite of their doing the best they can. PD creates many losses, some more obvious and some more subtle. Such losses should be accepted and new areas of activities should be organized. In this respect the support group can help”

“Care giving is also a physical challenge. A CG has to be physically fit. During the time of care giving you are being pushed often beyond your endurance. You may not sleep properly. Therefore a CG needs to take care of own self as well as of the PDP. To maintain physical health both should have food, sleep and exercise. It is not an option. It must happen. No one else is going to make it happen.” “You deserve to do more than just exist. Have joy and pleasure of your life. Select such activities that will ensure your existence beyond this disease. Bring in a paid help if you can. Use your resources to be creative and a problem solver too.”



SPEECH & PARKINSONS DISEASE

Ms. Pooja Singh – Speech Therapist

Dysarthria (difficulty in speaking) and Dysphagia (difficulty in swallowing) can be severely limiting symptoms of Parkinson's disease. They can be helped by seeing a speech therapist.

Until recently, traditional speech therapy has not provided sustained improvement; but a new program, called the Lee Silverman Voice Therapy Program, has been developed and has demonstrated significant value for people with Parkinson's. Ask your doctor to refer you to a speech pathologist experienced in administering the Lee Silverman Voice Therapy Program.

How can I improve my speech?

Speech – language pathologists can help people with PD maintain as many communication skills as possible. They also teach techniques that conserve energy, including non – verbal communication skills. Speech – language pathologists are also able to evaluate swallowing function and recommend changes as necessary.

How can I maintain and enhance my speech?

1. Choose an environment with reduced noise. It can be tiring to try to “talk over” the television or radio.
2. Speak slowly.
3. Be certain your listener can see your face. Look at the person while you are talking. A well – lit room enhances face – to – face conversation, increasing understanding.
4. Use short phrases. Say one or two words or syllables per breath.
5. Over – articulate your speech by prolonging the vowels and exaggerating the consonants.
6. Choose a comfortable posture and position that

provide support during long and stressful conversations.

7. Plan periods of vocal rest before planned conversations or phone calls. Know that fatigue significantly affects your speaking ability. Techniques that work in the morning may not work later in the day.
8. If you are soft spoken and your voice has become low, consider using an amplifier.
9. If some people have difficulty understanding you, the following strategies may help:
 - If you are able to write without difficulty, always carry a paper and pen as a backup so you can write down what you are trying to say.
 - If writing is difficult, use an alphabet board to point or scan to the first letter of the words that are spoken.
 - Spell words out loud or on an alphabet board if they are not understood.
 - Establish the topic before speaking.
 - Use telegraphic speech. Leave out unnecessary words to communicate the meaning of the topic.

What is nonverbal communication?

Nonverbal communication, also called augmentative and alternative communication (AAC), is a method of communicating without spoken words.

When communication needs cannot be met through speech, the following techniques can help:

- Make the best use of what speaking ability is left
- Use expressions and gestures to communicate.

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QUEST - A QUESTION OF ANSWERS

Q. My age is 60. I have PD for the last 10 years. What is your opinion on surgery?

A. Surgery, particularly Subthalamic Nucleus Deep Brain Stimulation, does significantly improve the motor symptoms of PD in advanced cases. It, however, should be considered only in those cases in whom PD medications no longer give relief either due to lack of efficacy or due to disabling dyskinesias (on-off).

Q. For dyskinesias which drug is used - Amantrel or Pacitane?

A. Dyskinesias are involuntary movements which occur with progression of Parkinson's disease and are due to PD medications, mainly levodopa. Pacitane does not help dyskinesias, but Amantadine (Amantrel) has been found to be useful in reducing dyskinesias in long standing PD cases.

Q. I have read an article that Nicotine patches reduce tremors. Please let us have your views.

A. To the best of my knowledge, Nicotine patches do not reduce the tremors of PD. The tremors which occur as part of a withdrawal state when smoking is stopped maybe helped by Nicotine patch, not PD tremors.

Q. Please give some practical guidelines about the use of the new drug Pramipex.

A. Pramipexole is a dopamine receptor agonist. Being a Non ergot drug it does not have many of the side effects of the older dopamine agonists like bromocryptine. It is useful in improving the motor symptoms of PD, both in the initial stages and in the more advanced cases. It is especially useful in young PD patients where we want to delay the use of levodopa as long as possible. As an added benefit, Pramipexole also has anti depressant properties and can improve the mood of PD patients. In some patients, it can cause excessive sleepiness.



EXERCISE IN PARKINSON'S DISEASE (Part -I)

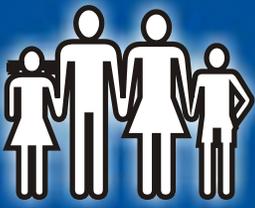
Time and again, PD patients have been told by various health professionals that exercise is the most important therapeutic aspect. In fact, when the three commandments of survival for human beings include breathing, eating, and sleeping, for a PD patient a fourth one gets automatically introduced: exercise.

The **benefits** of REGULAR exercise for a PD patient include the following:

- Increased cardiovascular fitness
- Prevention of joint deformity
- Improved joint mobility
- Improved coordination and balance, especially in walking.
- Increased muscle strength and flexibility
- Reduced muscle cramping
- Improved posture
- Improved control over gross motor movements, such as walking
- Reduced stress levels
- Greater confidence in performing daily activities.

A few **general recommendations** before starting off on any exercise program include the following:

- Normal exercises like walking, aerobics, stretching exercises should be performed daily.
- One should start off with at least 15 minutes of exercise daily, and progressively increase it by 5 -10 minutes approximately.
- Warm-up and cooling down exercises are very important. This could include marching in one place or stretching.
- Start with the easiest exercises first. Slowly introduce the more difficult exercises as your fitness increases.
- Try to perform each movement to the best of your ability.
- Stop and rest if you feel tired at any point during your exercise program, as overexertion can make your symptoms worse.



EXERCISE IN PARKINSON'S DISEASE (Part -I)

- If you suffer from fatigue, try exercising first thing in the morning.
- Try to make exercising fun. Suggestions include exercising with others or playing your favourite music.
- Practice everyday activities like dressing and eating. And when practicing “exaggerate” every movement needed to perform these daily activities.
- Stretching exercises should be a compulsory part of a PD pts regime.

A few **Safety precautions** PD patients should take include:

If you are at risk of falling or freezing (becoming rigid), general safety suggestions include:

- Perform your exercises sitting down.
- Hold onto a chair when performing standing exercises.
- Don't perform floor exercises if you can't get up by yourself.
- Only exercise when other people are at home who can help if necessary.
- Exercise with others.
- Ask for assistance from a family member or friend.

In the following issue of ‘Movement’, we will carry Part – II of this article, where we will present a sample exercise program targeting overall fitness, muscle flexibility, face, head & shoulders, arms & torso, hands & wrists, and legs.

(Adapted from : http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Parkinson's_disease_and_exercise?OpenDocument)



PAIN IN PARKINSON'S DISEASE

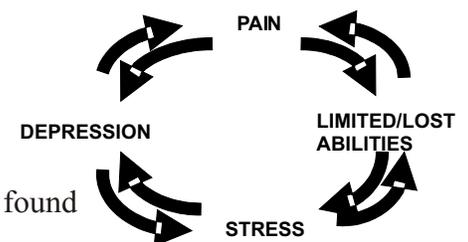
Descriptions of Parkinson's disease do not generally include the mention of pain. Yet, when carefully questioned, more than half of all people with PD say that they have experienced painful symptoms such as aching, stiffness, numbness and tingling at some point in the course of the illness. For a few of them, pain and discomfort are so severe that they overshadow the other problems caused by the disease. However, the reasons for this are that patients are usually unaware that pain could be associated with PD.

A PD patient could be suffering from various types of pain such as,

- **Musculoskeletal pain** which involves aching muscles, joints and body parts. Rigidity, lack of spontaneous movement, abnormalities of posture, gait and awkward mechanical stresses all contribute to musculoskeletal pain in PD. One of the most common musculoskeletal complaints is shoulder stiffness, sometimes called a frozen shoulder.
- **Central pain syndrome** which is presumed to be a direct consequence of the disease itself, is described by patients as bizarre unexplained sensations of stabbing, burning and scalding, often in unusual body distributions: the abdomen, chest, rectum, genitalia, or mouth.
- **Dystonic spasms** (painful cramps) are among the most painful symptoms that a person with PD may experience. Dystonia in PD may affect the limbs, trunk, neck, face, tongue, jaw, swallowing muscles and vocal cords, and most commonly feet and toes which may curl painfully. The most important step in evaluating dystonia is to establish its relationship to dopaminergic medication. Does the dystonia occur when the medication is at peak effect or its effects are waning? This will usually clarify the nature of the dystonia, and determine its treatment. Most painful dystonia represents an "off" parkinsonian phenomenon, and occurs early in the morning or during wearing-off spells.

Pain in PD can be due to various reasons such as,

- The “on – of mechanism” of PD, which is basically related to the effects of the medicine. Therefore, the underlying mechanism here is the level of dopamine, the brain chemical associated with PD.
- Another reason of pain in PD can be the “PD symptoms” such as tremors, rigidity and bradykinesia.
- Difficulty with sleeping and sleep disorders can cause pain too.
- However, the most common cause of pain is “Psychological Symptoms”. Depression, anxiety, panic, stress can all be an initial cause of pain, as well as, increase the potency of pain one is already experiencing. Various studies have found





PAIN IN PARKINSON'S DISEASE

that ALL kinds of pain have a psychological component attached to it. Therefore, it is this “hidden” source of pain that is considered the most important in the management of pain. One needs to understand and accept the Psychological components involved in pain, and this can be done through the pain cycle:

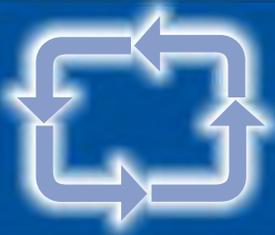
Management of Pain

For most PD patients, pain is not the foremost and overpowering problem and therefore it can be managed by the persons themselves with a few general tips. However, a PD patient should not assume that the pain they are experiencing is solely due to the disease. It could be due to an unrelated condition, which left undetected could prove very hazardous.

One can follow simple steps to decrease the feeling of pain.

- **Exercise & Physiotherapy** – can help strengthen muscle, provide a general sense of well-being, increase mobility etc. These include general exercises such as walking, jogging, aerobics, swimming, cycling. Exercise helps by releasing endorphins, the body's natural painkilling substances. Physiotherapy is a more specialized way of dealing with pain through tailor - made exercises & ‘education’ involving the teaching of the right posture, right gait, body mechanics, importance of rest, and methods of energy conservation.
- **Simple Home Remedies** – for local treatment of pain, one can use these simple remedies.
 - Hot water compress which increases circulation and thus reduces pain.
 - Cold / ice packs which reduce swelling.
 - Dried Ginger – Water pack.
 - Asafetida – Castor oil pack.
- **Stress – Management techniques** deal with the psychological components of pain, thus providing relief. These include,
 - Relaxation where several methods exist, & the most common known as Progressive Relaxation (by Edmund Jacobson) involves progressively targeting, tensing and relaxing various muscle groups in the body, working ones way upward from toes to head.
 - Guided imagery where thinking of a relaxing environment and taking yourself there – i.e. lying on a tropical beach – may facilitate relaxation.
 - Thought Stopping / Distraction where instead of asking yourself “how was the pain today?” Rather ask yourself – what activities were you involved in? How did you feel?
- **Massage** is another technique which decreases spasms and thus relieves pain.

Thus adapting from a William Styron quote, “Pain can’t hurt you unless you let it”.



PDMDS' ANNUAL PATIENT – CAREGIVER – SEMINAR

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and international representations & art classes all involving the PDMDS and showed the audience interesting pictures of these activities. She also spoke about the vision of the PDMDS to start a multi-disciplinary rehabilitation centre for the benefit of the patients.

Dr. Jimmy Lalkaka gave a presentation on “Drugs for PD – New and Old”, wherein besides informing patients of existing anti - PD drugs, he also spoke about their motor and non - motor side-effects and measures to be taken for their optimal use.

Dr. Rajvi Mehta of Iyengar Yogashraya spoke about the importance of Yoga in PD, and how Yoga and which specific types of asanas help in reducing the symptoms of PD. This she did through a powerpoint presentation of her research study that had been conducted by the PDMDS and Iyengar Yogashraya, where PD patients had undergone a 3 month yoga course.

This was followed by another interesting presentation by Dr. Maya Sanghi, Speech Therapist at Nair Hospital. She spoke about the physiology & anatomy of the process of speech and the kind of speech problems and deficits that PD patients face. She further spoke about the role of speech therapists in PD, and demonstrated a few basic exercises.

The PDMDS was also glad to welcome members of the Pune support group, who had made the effort of shooting a video clip of various informative books and catalogues provided to them by the American PD

Association. The patient organizer of the support group Mr. Madhusudan Shende, presented this clip to the audience.

This was followed by an interactive and enjoyable panel discussion and question and answer session, which was coordinated by Dr. Sarosh Katrak, President of the PDMDS. Other panel members included Dr. Charulata Sankhla, Dr. Neeta Mehta, and Dr. Pettarusp Wadia (Neurophysicians); Dr. Rajvi Mehta (Yoga Instructor); Dr. Maya Sanghi (Speech Therapist); and Ms. Roshan Vania (Physiotherapist).

Dr. Singhal then thanked all those who attended and also expressed gratitude to the organizers and the sponsors.

During the refreshments and snacks which followed, the audience had the opportunity of enjoying the beautiful collection of art work, including paintings, pillow cases, scarves etc done by a PD patient Mrs. Shail Pandey. Also on display were the paintings of our amateur patient – artists, Mrs. Ayaz and Mr. Baker, who attended our art classes.



Informal Interactions.



continued from page 2...

specially if he happens to be a member of the family, perhaps a spouse. He becomes critical of other family members not doing enough. They may be compelled to stay away from friends, family or well wishers. The ever increasing cost of treatment, unplanned illness & even the care giver's own age & needs are some realities that indeed distort human thinking. Under such circumstances, both patient & care giver abandon group meetings, reading about their illness & in some cases, even a periodic visit to the neurologist. Here my advice is to join an active support group in your area. 'Select such activities that will ensure your existence beyond this disease'.

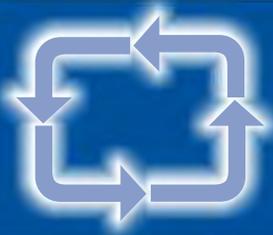
EXERCISE :

Within the limits of their capability, everyone benefits from exercising. PD patients have particular requirements both to maintain their present strength & flexibility and prevent degeneration of muscles & joints. Patients have to make an increased level of effort to carry out normal tasks. They may feel fatigue, become slower & drag their feet. This is due to temporarily using up neuro chemical – dopamine. Exercise helps control body weight, improves cholesterol metabolism, strengthens muscles, improves flexibility & posture and helps balance, coordination & protects against loss of bone density. The risk of Osteoporosis is increased with age, ovarian removal(in females), chronic oral cortisone use, early menopause, insufficient dietary calcium & excess alcohol & tobacco use. Estrogen therapy started several years after menopause to the end of the patient's life prevents osteoporosis. However, always remember, we're in the 'slow – lane', & our balance is not getting any better with time.

DYSARTHRIA (SPEECH) & DYSPHAGIA (SWALLOWING) :

Not all Parkinsonians develop difficulty with speech. And those who do, they may be of varying types & degrees. In some cases the voice may be uniformly very weak, in others it is strong to start, but fades away as the sentence progresses. The voice may be monotone, lacking expression or intonation. Speech may lack clarity & precision due to difficulty in articulating clearly. Where as traditional speech therapy could not provide sustained improvement, a new program called the 'LEE SILVERMAN VOICE THERAPY PROGRAM' continues to show great promise for Parkinsonians. Read about it in this Update.

Parkinson's Disease and Movement Disorder Society (PDMDS), a 'charity society' brings you this Update as one of its commitments, to bring about awareness & information on movement disorders, with the objective of helping the patient, his caregiver, the social worker and, of-course the medical community to collectively improve the quality of life of those afflicted. All those interested in knowing more or helping promote the cause may call me on phone 65761242, or e-mail at : guru_kohli@rediffmail.com Remember, You're never alone.



SPEECH & PARKINSONS DISEASE

Ms. Pooja Singh – Speech Therapist

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Nonverbal communication can help people with speech difficulties actually speak better by reducing the frustration of being unable to communicate and allowing the person to be more relaxed and come across in a more understandable manner.

What if I have an emergency, how will I communicate?

- Use an intercom system or a bay monitor to alert others that there is an emergency.
- Use bells or buzzers if you are not able to speak. Use “codes” that signify urgency. For example, a tinkling bell may mean, “I’d like company”, while an air horn means there is an emergency.
- Carry a portable phone that is equipped with pre – programmed numbers.
- Pre – program all your telephones so they can automatically dial the necessary emergency number.
- Consider a “Life Call” button if you spend time alone.

In Early or Late PD

Ropiro

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0.50
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2

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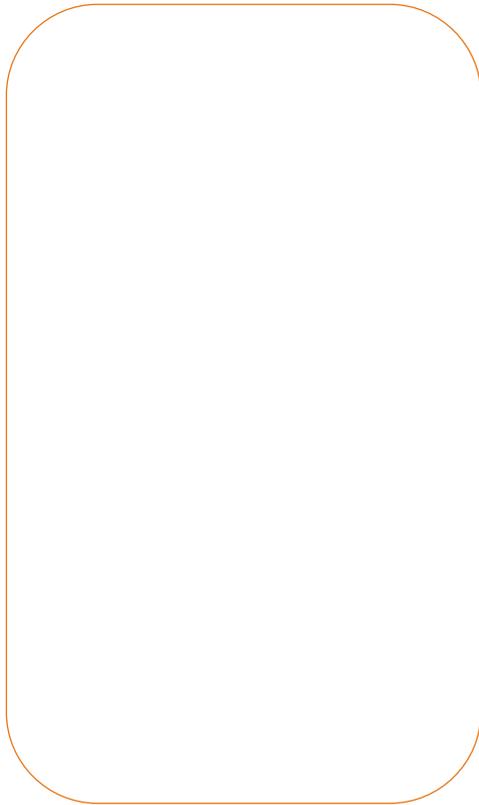
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 6, Jasville, 1st Floor, Opp. Liberty Cinema,
 Marine Lines, Mumbai – 400020.

A different journey awaits each one, but our destination is the same.

As the PDMDS moves further forward in this journey, our destination has been to reach out to you. For some of us the journey is through bringing you information, for others it is through answering your doubts, for still others it has been through bringing each of you closer to each other. Similarly, your destination has been to deal with the disease, but the journey through it has been different for each of you. We at PDMDS are extremely keen on knowing what your experiences have been. In a similar vein we would also like to know what you have taken from *movement* – your comments and criticisms; what you would like to see in *movement* – your suggestions and questions. So please write to us.

Besides *movement*, localized support groups, seminars, national and international representation have helped PDMDS move closer towards its goal to “Make the PD World Smaller.” To make it still smaller we invite non-member patients to become a part of our society. Moreover, none of our existing patient-members should have to miss out on being a part of the activities or receiving an update of *movement* because of a change in residence. Therefore keep us informed of any change in address or telephone numbers.

We further invite any organizations or support groups associated with PD & movement disorders, anywhere in the world, to get yourselves enrolled in our mailing list, and we request enrollment into your mailing list.

PDMDS’ consistent goal, being a ‘Charity Society’, has been to make the healthcare system accessible, to spread awareness of tried but dormant ways, and discover new ways of making a difference in the lives of patients and caregivers. It goes without saying that funding is required for these purposes, and therefore we request those well-wishers interested in making donations to our efforts and cause, to contact us.

If you wish to correspond with us for any of the above, or require any information regarding the same, the contact details are given as follows:

Address all correspondence to:
THE PARKINSON’S DISEASE & MOVEMENT DISORDER SOCIETY,
 6, Jasville, 1st Floor, Opp. Liberty Cinema, Marine Lines,
 Mumbai – 400020.
 e-mail: e.pdmds@gmail.com
 Call Navaz Irani: Phone No. - 9892149259.