

MOVEMENT

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



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EDITOR: G. S. KOHLI

CO-EDITOR: DR. J. A. LALKAKA

7th World Parkinson's Day International Symposium

Mumbai awaits with pleasure the arrival of delegates from all over the world for an international event being held for the first time in India, **7th World Parkinson's Day International Symposium**. Over 35 specialists will converge here to share their views & vast & varied experiences on the latest in PD & its treatment. We warmly welcome them all. The Indian neurological community is extremely talented & enlightened. The Indian patient, caregiver & social worker are fully conscious of the enormous help that **support groups** can provide & are well focussed & motivated. The cause of PD will undoubtedly be promoted further with the resources these experts bring with them. We welcome them all including representatives of various international PD associations.

Mary G. Baker - MBE

Serving her fifth term in office as President of the European Parkinson's Disease Association (EPDA) since 1992. EPDA promotes international understanding of PD, & has 35 European Parkinson's Patient Organizations as members. Retired as Chief Executive of Parkinson's Disease Society of U.K. after 18 years of dedicated service. Patient editor of the BMJ, member-ABPI Code of Practice, Honorary Doctorate – University of Surrey. Recipient of several awards for work in neurology, specially in PD, including European Woman of Achievement 2000 & Human Communication International 2001.



Message : For patients & caregivers – Living with PD.

Several changes to society in the last three decades have had implications for those connected with PD.

- Changed role of voluntary organizations – importance of listening to the needs of patient & family.
- Demographic changes & resultant increased number of the elderly & frail.
- Expanding global population with brain disease.
- Sharper focus on needs of the aging neurologically afflicted population.

Mark Hallett - MD

MD from Harvard University & trained in Neurology at Massachusetts Gen. Hospital. Fellowships in Neurophysiology at National Institutes of Health & Institute of Psychiatry in London. Since 1984, Chief of Human Motor Control Section, National Institute of Neurological Disorders & Stroke, where he pursues wide-ranging research. Currently Vice-President of the American Academy of Neurology, & Editor-in-Chief of Clinical Neurophysiology. He is the past President of the prestigious Movement Disorder Society. He will be speaking on the physiology of bradykinesia.



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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.

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Editors' Page

I join Dr. Jimmy A. Lalkaka in our pleasure to bring you *MOVEMENT*, a quarterly update on what you would like to know most about – Parkinson's Disease & other movement disorders. But that's not All. We intend to bring you a much larger picture with concerted focus on the **patient's needs & requirements**. *MOVEMENT* is brought to you by the Parkinson's Disease and Movement Disorder Society (**PDMDS**). It is a 'charity society' founded in 2001, whose list of office – bearers (see left) reads like the 'who's-who' in Indian neurology, and serving to link the various support groups for Parkinson's Disease & other movement disorders in the country. Its **main objectives are to improve the care & treatment of the afflicted & disseminate knowledge amongst the medical community, public, caretakers & patients**. No wonder it brings over 35 international experts to Mumbai in December, 2003 for a First- '7th World Parkinson's Day International Symposium', 2 full days devoted to Parkinson's Disease. There is also a separate parallel 2 day session for patients & caregivers. This it is organizing as the main sponsors along with no other than the World Health Organization & the Movement Disorder Society as co- sponsors - a big step forward for neurology in India.



G. S. Kohli

In the short span of its existence, the **PDMDS** has taken some important initiatives. This year, 2 very successful public meetings were held with large participation. The first, to celebrate World Parkinson's Day on 11th April, & the second on 13th September, the theme of which being 'Living with Parkinson's Disease'. (For more details on the meetings' activities, see '**Inside This Update**' on page 1).

At *MOVEMENT*, the patient, caregiver & social worker along with the medical community are our only 'customers'. Through it, we intend bringing you updates on new drugs & surgery, with their efficacy determined by reputed studies, serialized essays on 'Coping Strategy' for day to day problems & the recurrence of symptoms, news & views from other support organizations in India & overseas, information on up-coming meetings, support groups operating in your vicinity, drug stores we have arranged for your requirements at discounted prices, your rights as a 'disabled' person, availability of concessions on travel, Income Tax etc. & how to avail of them, assistive devices for your safety & comfort & much more.

For more information, **visit us at our website** (see bottom of page 1).

Above all, we await a response/ your views on WHAT YOU WANT.

For more urgent issues, contact me, **G. S. Kohli on our HELP-LINE SERVICE on Phone # 56959180. Remember, You're never Alone.**

Sorry, I slipped introducing myself at the outset. I'm a Chartered Accountant by qualification, & a young onset PD patient diagnosed 23 years ago at the age of 25. For the last 14 years I have been helping PD patients in a number of ways. So, let me help you.

Message from Dr. T. N. Mehrotra

President, PDMDS

I am pleased to know that the PDMDS has started its own news-journal, "MOVEMENT". This is for the benefit of patients afflicted with Parkinson's disease and other movement disorders and their caregivers as well as for the public and the medical community at large. This inaugural issue happily coincides with the 7th World Parkinson's Day International Symposium which is being held at the Taj Mahal Hotel, Mumbai on 6th and 7th December, 2003.

I extend my hearty congratulations and best wishes to the editors of the "Movement". I hope that it will help to achieve the objectives of the Society.



About PDMDS

Dr. B. S. Singhal, Hon. Secretary, PDMDS

Parkinson's Disease and Movement Disorder Society (PDMDS) was formed in the year 2001. It is registered under the Societies Registration Act of 1860 and has its registered office in Mumbai.

PDMDS is an all India body serving to link the various support groups for Parkinson's disease and movement disorders in India. Its main objectives are to improve the care and treatment of patients with Parkinson's disease and movement disorders and to disseminate knowledge amongst the medical community, public, patients and caretakers.

Besides the founder members, the categories of membership include

- a) Institutional members i.e. any association or organization of Parkinson's disease and movement disorders having a minimum of 25 members and working for the welfare of patients of Parkinson's disease and movement disorders. Any medical person, patient, caregiver or any person interested in the welfare of the patients can become a member of the support group in his or her own region and, through it, be represented in the PDMD Society.
- b) Invitee members.
- c) Honorary members.



...continued from Page 1

Prof. Jin-Soo Kim-MD

Professor of Neurology since 1985 at Yonsei University Medical Center, Seoul, Korea. A distinguished academic career includes MD in 1964, Dr. med. in 1975 and Dr. med. habil. in 1979. Recipient of several awards, including the more recent Moran Merit of Civil Order in 1999 and Cross Merit of Order in 2000. He is on the Editorial Board of the Journal of Neurology, Psychiatry & Brain Research. His major research interests include Neuronal biology and applications of newer biological techniques and neuropsychopharmacological drugs in problems of neuronal biology. He was the organizing chairman for the Asia Pacific Parkinson's Disease meeting held in Seoul, Korea in October 2003. He will be speaking on the management of Parkinson's Disease in Korea.



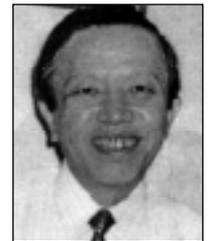
Dr. Shu-Leong Ho –MD, FRCP

Associate Professor and Chief Neurologist at the University Department of Medicine, University of Hong Kong since 1997 and Honorary Consultant at Queen Mary and Tung Wah Hospitals. He obtained his MD in 1995 and subsequently elected to the Fellowship. His interest lies in treatment of PD with reference to pathogenesis. He organized the Asia Pacific Parkinson's Disease meeting held in Hong Kong in 2001. He will be presenting a paper on the epidemiology of Parkinson's Disease in Asia.



Yoshikuni Mizuno-MD

Professor & Chairman of the Department of Neurology of Juntendo University School of Medicine, Tokyo, Japan, since 1989. He is either a fellow or member of the Japanese and American Neurological Associations, American Academy of Neurology & the Movement Disorder Society. He has published more than 200 articles and is on the Editorial Board of several journals including Movement Disorders & Neural Transmission. His interest lies in etiology and pathogenesis of PD. His group have recently identified the gene for an autosomal recessive form of young onset familial PD. He organized the World Parkinson Day symposium in Tokyo in the year 2000. He will be discussing the genetics and aetiopathogenesis of Parkinson's disease.



World Parkinson Day Celebrated – 11th April, 2003

- Dr. J. A. Lalkaka



Panel of experts answered questions from participants

To commemorate World Parkinson Day, the Parkinson's Disease and Movement Disorder Society of India (PDMDS) organized a symposium "Living with Parkinson's Disease" on 11th April 2003 in Mumbai. This was meant to be an interactive session with PD patients, their caregivers and other people interested in PD.

The S. P. Jain Auditorium at Bombay Hospital (the venue for the meet) was packed with about 425 people. Dr. J. Lalkaka, (Hon. Treasurer, PDMDS), welcomed the gathering. He apologized for the absence of Prof. B. S. Singhal (Hon. Secretary, PDMDS) who was invited to participate in the World Parkinson Day celebrations in Moscow. Dr. Lalkaka outlined the main objectives of the Society and gave a broad outline of the management of PD including the recent advances in genetics and drug therapy. An edited video clipping of the famous Donahue talk show featuring Phil Donahue in conversation with eminent PD specialists (William Koller and Abraham Lieberman) and PD patients was much appreciated by the audience. They were amused to know that they shared the disease with celebrities like Mohammed Ali, Pope John Paul, Adolf Hitler, Yasser Arafat, Mao Tse Tung and Janet Reno (ex US Attorney General).

Dr. Ashit Sheth (Hon. Psychiatrist) then discussed the problems of depression and anxiety in PD patients. Depression was common in PD patients, affecting nearly 40% and was the most important factor affecting the quality of life, not only for the patients but their caregivers as well. Besides antidepressant drugs, Dr. Sheth stressed on

psychosocial support, counseling and help from support groups.

Dr. B. K. Dastur (urologist) then addressed the problems of constipation and urinary disturbances which are frequently encountered in PD patients. She spoke on simple measures which could be taken to alleviate these problems. Anticholinergic drugs like trihexyphenidyl were likely to cause urinary retention and constipation, especially in elderly males over 70 years. She strongly advised against taking this group of drugs in elderly males. She also mentioned that a medical opinion could be sought to rule out coexisting prostatic enlargement.

After Dr. Dastur's talk, Mr. Gurbindar Singh Kohli addressed the audience. Mr. Kohli is himself a young Parkinson's patient. His PD was diagnosed in 1981 when he had just completed his chartered accountancy examination successfully. Despite his disease, he worked for 16 – 18 years with distinction in renowned firms like Pfizer and Castrol. Even after 22 years of the illness, he has managed his disease so well, that he is able to lead a near normal life with no assistance. He gave the gathering several useful tips on the diet to be followed, the types of household appliances that could be used and simple modifications in daily routine which could significantly help PD patients. His speech was very well received by the audience who felt he was a source of inspiration to them. Some essays written by Mr. Kohli on 'Coping Strategy' for some of the secondary symptoms of PD were also distributed. Encouraged by the response, 'Coping Strategy' will continue to be feature in a serialized manner for the benefit of the readers of *MOVEMENT*.



G. S. Kohli shared his experiences on PD with keen listeners

Mr. Kohli's talk was followed by a lively question and answer session with a panel of eminent neurologists. Dr. S. M. Katrak, Dr. Nirmal Surya, Dr. Charulata Sankhla, Dr. Satish Khadilkar, Dr. Ashit Sheth and Dr. Jimmy Lalkaka participated. Scores of written questions were put to the panel. Problems of freezing, hallucinations, falls, excess salivation, difficulty in swallowing, sleep disturbances, surgical options and allied conditions like Progressive Supranuclear Palsy were all discussed patiently and lucidly by the panel. Though the language of communication was English, liberal use of Hindi was resorted to for the benefit of many in the audience.

A much needed coffee break followed this session. It enabled the patients to stretch their legs and move about. This interval also gave an opportunity for direct interaction between the doctors and PD patients and caregivers.

After the break, the audience was introduced to Dr. Roshan Vania, the physiotherapist. She and her band of assistants emphasized the role of exercise and physiotherapy at all stages of PD. A short video was followed by a practical demonstration of trunk, limb and facial exercises.

The meeting concluded with a vote of thanks. The general consensus of the audience was that the meeting was informative and useful and that such activities should take place on a regular basis in future.

HOPE & HELP - Dombivli

Support Group for Parkinson's Disease

- Dr. B. Negalur

I remember my first patient suffering from Parkinson's disease many years ago. "Doctor, somebody has cursed me! My life has virtually ended I cannot write, cannot sign my cheques, cannot walk fast. I feel inhibited shaking hands or meeting anyone, especially my friends. This tremor in my hands has finished me", he said. "But at least you are not paralysed. You can still move although less than before. With a little co-operation from you and a positive attitude and with medication and exercise you will live again fruitfully" was my reply.

Over the years I saw more and more similar patients. Some fighters, some helpless and some needing assistance to fight. "Hope and Help" group for Parkinson patients was thus born on April 11th 2002-World Parkinson Day in Dombivli-Prathamesh Hospital, for although Darwin's "Survival of the fittest" is true, mixing the fittest to lift the helpless and give hope both physically and psychologically became our motto.

Parkinson's disease causes various grades of disability in movement and so patients often face difficulty coping with it. It could also be hard for them to ask questions or talk about their problems with family or friends. When new patients see others like them living with hope and leading a quality life, it boosts their morale and makes them emotionally strong. Similarly family and friends also change their outlook and become more and more supportive and understanding to the patient's needs. "Hope and Help" support group of PDMDS is a common forum to share experiences and

feelings and discuss solutions to common problems faced by patients. Exchange of ideas motivates patients and their caregivers to keep a positive attitude and never give up hope. Today our group has around 44 members who have immensely benefitted both physically and emotionally. The group has created a teaching programme to spread awareness about the disease and educate patients. We also have physiotherapy sessions where members exercise in a group. Sometimes we collect to have a fellowship meeting. The future is bright. Let us not give up hope. Let us see a smile on every Parkinson face. Help to give hope.

For more details, contact :

*Dr. Benny Negalur, Prathamesh Hospital,
M.G. Road, Dombivli (W) - 421 202*



*Dr. Negalur (Second from left) with some
'Hope & Help' members*

Below the Tongue Atropine Drops for Drooling in Parkinson's

Sialorrhea (drooling) is a relatively common symptom in idiopathic Parkinson's disease and related conditions for which most of the accepted treatments are either highly invasive or may cause substantial systemic side effects. This study describes an open-label pilot study of sublingual (below the tongue) atropine drops for the treatment of sialorrhea in 7 patients (6 with Parkinson's disease, 1 with progressive supranuclear palsy). Participants demonstrated statistically significant declines in saliva production, both objectively and subjectively. Self-reported drooling severity showed a significant decline between baseline and 180 minutes, and between baseline and 1 week. Objectively measured saliva production decreased significantly between baseline and the 1-week follow-up. Delirium occurred in 1 patient (concurrent with a urinary tract infection), and 2 patients experienced worsening of hallucinations (active hallucinosis was concealed by both individuals to allow participation in the trial). The remaining trial participants did not experience any anticholinergic side effects. This trial shows that, in selected patient populations, sublingual atropine is a simple and inexpensive treatment for sialorrhea associated with parkinsonism.

(Sublingual Atropine for sialorrhea secondary to parkinsonism: A Pilot study

H. Christopher Hyson, MD (1), Andrew M. Johnson, PhD (2), Mandar S. Jog, MD (1)

(1) Movement Disorders Program, London Health Sciences Centre, London, Ontario, Canada

(2) University of Western Ontario, London, Ontario, Canada.

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Watch Weight Loss – a 'Pointer' in Parkinson's

Weight loss is common among PD patients. Beyer and colleagues showed that PD patients were 4 times more likely to reported weight loss greater than 10 pounds compared with controls (normal people), and the weight loss was correlated with the stage of the disease.

The paradox that PD patients lost weight as their energy intake increased suggests that the weight loss is caused by increased energy expenditure. This argument is supported by clinical observations that PD patients have higher energy expenditure than controls.

Higher resting energy expenditure in some PD patients was found to be related to severe muscle rigidity. Furthermore, body mass index of PD patients was inversely correlated with their clinical dyskinetic severity, and in a separate study, significant weight gains were observed in PD patients after pallidotomy, which was associated with the improvements of some cardinal manifestations.

It was found in this prospective study that PD patients began to lose weight several years before the disease is diagnosed despite an increased energy intake, suggesting that energy expenditure increases early in the course of PD. Further investigations are needed to assess whether this increase in energy expenditure is explained by early symptoms of the disease or whether it results from an underlying metabolic defect in PD patients.

(Weight Loss in Parkinson Disease

Honglei Chen MD (first author)

Annals of Neurology 2003 volume 53 page 676.)

P D M D S Meeting at Patkar Hall - 13th Sept., '03

-Dr. J. A. Lalkaka

13th September '03 - Patkar Hall in South Mumbai was the venue for the Parkinson's disease support group meeting organized by the **Parkinson's Disease and Movement Disorder Society (PDMDS)**.

More than 400 Parkinson's disease (PD) patients and their caregivers attended. The meeting began with a recitation of hymns by Mrs. Bavkar (spouse of a PD patient) invoking the almighty's blessings. Dr. B.S. Singhal, Hon. Secretary of the PDMDS then welcomed the gathering. He outlined the objectives of the PDMDS and gave a brief outline of future programs and measures for the welfare of PD patients.

A short documentary film on the world PD charter was then shown. It was a moving film showing eminent personalities of the world like Lady Diana, Tony Blair, Valdimir Putin and opera celebrity Pavarotti endorsing their support for PD. The boxing legend Mohammed Ali was shown holding aloft the Olympic flame.

An interactive question and answer session conducted by Dr. Singhal then followed. A distinguished panel of neurologists (Drs. J. Lalkaka, N. Surya, C. Sankhla, S. Khadilker & B. Negalur) and Mr. G. S. Kohli answered the several questions and discussed the various problems put forth by members of the audience.

At the meeting, 'Food Guide', a booklet listing the moisture, protein & fat contents of some 450 common food items compiled by Mr. Gurbindar Singh Kohli was distributed. It helps patients & caregivers to monitor the total protein intake, for effective absorption of levadopa through the day.

Mr. G. S. Kohli is a well-known "young" PD patient himself, who has devoted his time caring for other PD patients.

The session was then followed by a short film on Mr. Kohli. This film was shown on 'Doordarshan' TV in the popular program "Strivers and Achievers". In fact Ms. Kunika Lall, the charming Hostess & Producer of the TV program, was present at the meeting and Dr. Singhal invited her on the stage to speak a few words to the audience. Mr. Kohli then announced the formation of the **Mumbai Parkinson's Disease Support Group (MPDSG)**, a group formed by him, over a hundred members of which were present at the meeting wearing MPDSG badges. Thereafter, the affiliation of MPDSG with PDMDS was announced. Two members of the MPDSG, M/s. M. L. Mehra, & K. R. Angwalkar and Mr. Balwant Parekh of PDMDS also addressed the audience and shared their experiences on living with PD. Dr. Benny Negalur, eminent neurologist in Dombivili then briefly outlined the activities of a PD support group started by her in Dombivili.

After another question and answer session with PD patients and the panel neurologists, it was time for the physiotherapy session. This was conducted by Dr. Roshan Vania and her team of dedicated physiotherapists. It was much appreciated by members of the audience.

The meeting ended with a vote of thanks. Several members of the audience felt that such meetings were extremely informative and hoped that they would be organized at frequent intervals. So, here's looking forward to more useful meets in future.

Surgical Deep Brain Stimulation -Taking an Informed Decision

- G. S. Kohli

In a number of Parkinson's Disease fora including the meetings of the Parkinson's Disease and Movement Disorder Society (PDMDS) and Mumbai Parkinson's Disease Support Group (MPDSG) as also by several letters and phone calls, I have been asked a large number of questions about 'Deep Brain Stimulation' (DBS), a surgical procedure which has been reported in the press of late. Brief answers were provided. However, I consider it important that any surgical intervention be **exhaustively and accurately understood, specially the risk factors and side-effects**. In the interest of the patient, caregiver and the family physician, I promised ALL, that I would answer their questions in detail in an upcoming opportunity. I'm doing so now in this update. This, however is not a comprehensive treatise on the subject. Often spoken of and written areas have been omitted for two reasons – repetition and paucity of space. Questions also have not been printed for the same reasons. However, readers will find their questions answered in the paragraphs that follow.

(Drs. C. Warren Olanow and Mitchell F. Brin of the Department of Neurology, Mount Sinai School of Medicine, New York, New York 10029, U.S.A. in 'Surgical Therapies for Parkinson's Disease – A Physician's Perspective', pages 421 to 433 of *Parkinson's Disease: Advances in Neurology Vol. 86*. Edited by Donald Calne and Susan Calne. Lippincott Williams & Wilkins, Philadelphia © 2001.)

Deep brain stimulation (DBS) as a treatment for Parkinson's Disease (PD) was introduced by Dr. Benabid and his colleagues in Grenoble, France (*Benabid AL, Pollak P, Louveau A, et al.*).

Optimal stimulation settings are determined by varying the electrode contact (each electrode has four individual contact sites, which can be stimulated in monopolar, bipolar, or multipolar configurations),

voltage, pulse width, & with a stimulation frequency of 100 to 180 Hz., coupled with a pulse width of 60 to 210 per sec. and voltage of 2 to 4. The lowest voltage that can provide maximal benefits with tolerable adverse effects is typically selected to conserve battery power.

The precise mechanism whereby DBS induces benefit is not known, but it is generally thought to act through depolarization blockade, jamming of abnormal neuronal firing patterns, promoting release of inhibitory neurotransmitters, or backfiring through inhibitory structures such as the globus pallidus, pars externa (Gpe).

DBS has the advantage that it does not require making a destructive lesion in the brain, can be used bilaterally with relative safety, and can be adjusted to try to improve benefits and reduce side effects.

Controlled trials of DBS with electrodes implanted into the Vim nucleus of the thalamus demonstrate the value of this procedure for patients with tremor dominant PD and essential tremor (*Benabid AL, Pollak P, Gervason C, et al. & Blond S, Caparros-Lefebvre D, Parker F, et al.*). More recently, interest has shifted to stimulation of the Gpi and subthalamic nucleus (STN) as primary targets in PD based on preclinical and clinical evidence indicating that such procedures may improve the entire constellation of parksonian motor dysfunction.

Adverse events of the procedure are associated with the surgical procedure itself, with the device, and with stimulation. The latter tend to be transient and of minimal clinical significance and can usually be controlled by adjusting the stimulator settings. In studies, **intracerebral hemorrhage has been the most serious problem.** This was associated with the use of antiplatelet agents, **the number of needle passes, and the experience of the surgeon.**

Transient ballism has also been reported (*Limousin P, Pollack P, Hoffmann D, et al.*).

There has been occasional reporting of **reactive fibrosis** associated with the implanted electrodes.

Problems associated with the device—dislodgement of the electrode, skin erosion infection, and mechanical problems with the electrical system such as **fracture of the implanted materials** have also been reported.

Stimulation itself can induce adverse effects, e.g., paresthesias, dystonia, pain, and abnormal eye movements. Theoretically, these could be controlled by adjustment of stimulation parameters. However, this is the **most challenging of tasks associated with DBS, involving several visits to the neurologist, and an equal number of hours per visit. Adjustments may again need to be made after a time lapse. Also, this requires expert help, patience, knowledge and understanding and experience.**

Again, theoretically, the patient can himself/ herself make day and night conditional adjustments per the requirement. However, **I am yet to encounter a case where this has happened.**

The battery is sealed within the stimulator, and having a limited life, has to be **replaced typically within 5 years.**

Further investigations of DBS are warranted to **define the long – term safety and efficacy and differential benefits** of stimulating different target sites to determine if DBS of the STN does indeed influence the natural history of PD and to define the precise mechanism whereby high-frequency stimulation induces its clinical effects.

As per the ‘Mount Sinai Approach’, in most instances, surgery is recommended because of disability related to the motor complications associated with chronic levodopa therapy. Their philosophy is to utilize strategies in the early stages of the disease that offer the best potential for reducing the risk of developing these motor complications. These include using putative neuroprotective agents, initiating symptomatic treatment with dopamine agonists, and administering

levodopa with a COMT inhibitor (*Olanow CW, Obeso JA*). **However, once motor complications develop that are not readily controlled by medical therapies, surgery is considered.**

Some important aspects to be borne in mind are :

1) Ensure that the **correct diagnosis** has been made. **Many Parkinsonian patients who are referred for surgery are doing poorly because they have atypical parkinsonism.** This diagnosis should be considered in patients who have an accelerated course, early onset of speech and balance dysfunction, lack of a good response to levodopa, prominent autonomic disturbances, eye movement disorders, or specific MRI abnormalities. Presently, there is **no evidence to suggest that any of the surgical procedures are of value for patients with atypical parkinsonism.**

2) Obtain pre-operative neuro-psychological testing. Only patients with relatively preserved cognitive function are considered for surgery **in order to minimize further impairment risk as also to obtain proper informed consent.**

3) Bilateral brain lesions being a risky proposition, simulation is generally preferred, specially where bilateral procedures are required, or if previous ablative procedure has been performed.

4) DBS of the STN is preferred to that of Gpi (for dyskinesia), or of the Vim nucleus (for tremor) because of better results & the advantage of controlling other PD symptoms if they appear in future.

(Dr. Lauri V. Laitinen of the Department of Neurosurgery, Sophiahemmet Hospital, S-144 86 Stockholm, Sweden in ‘Surgical Treatment for Parkinson’s Disease Over the Last Decade’, pages 455 to 460 of Parkinson’s Disease: Advances in Neurology Vol. 86. Edited by Donald Calne and Susan Calne. Lippincott Williams & Wilkins, Philadelphia © 2001.)

Dr.Laitinen expresses his concern with STN surgery, as this small nucleus lies embedded among sensitive structures such as the ansa and fasciculus lenticularis, the mammillothalamic tract, and the

pyramidal tract. **Even a small hemorrhage in this region can interfere with vital functions.** Dr. Hariz has observed **aphonia** following STN stimulation, which did not disappear when the current was switched off (M. I. Hariz, *personal communication*). **Post-operative confusion** was reported by the Grenoble group in one of their first three patients (*Limousin P, Benazzouz A, et al.*). **The stimulator cables may break, and complications from infections are not rare.** He therefore advises that **STN stimulation must not be tried by neuro-surgeons who are beginners in stereotactic surgery.**

DBS is a recurring and expensive surgical procedure. Dr. Laitinen elaborates that the **cost of the surgery** as also the **cost of the instrument** is high. As the patient **requires frequent medical or surgical follow-ups**, the cost over a period of ten years itself, exceeds the cost of a unilateral unit by

about 20 %. **The unit and the battery have to be replaced every three years.**

CONCLUSION :

Firstly, NO surgical procedure or drug therapy known as of date are a CURE for PD.

Secondly, drug therapy must be the route of choice for the management of the symptoms of PD in the early stages of the disease, and even in the advanced stages, any surgical procedure must be considered only for PD patients whose symptoms cannot be satisfactorily controlled with medical therapy. Another important fact to keep in mind is that the optimal symptomatic control obtained with surgery can at best be as good as the best titration can offer. Surgery, therefore should never be looked at as an alternative to medical therapy.

The Quest

- A Question of Answers

I am 47 years old and suffering from Parkinson's disease since 1999. My day starts at 6 am and ends at around 10 pm. I am taking medicines 4 times a day. But of late my medicine effect lasts for only 2 ½ hours which was earlier more. Why is this happening? Is there any alternative for the above mentioned problem? In between dosages, I find myself very uncomfortable.

- Mr. S. Vaidya, Mumbai

The problem you are facing is end-of-dose motor deterioration. This is a common problem faced by most Parkinson's disease patients who have been on levodopa for more than 2-3 years. It would be best to consult the neurologist who is treating your parkinsons's disease. The options that can be considered are a) increasing the frequency of levodopa dosing or b) taking controlled-release levodopa or c) adding another drug like a dopamine agonist (ropinirole or pramipexole or bromocriptine). When COMT inhibitor entacapone is available in India, it can be a useful drug to take along with levodopa in your situation.

My father is suffering from Parkinson's disease since the last 4 years. He is 65 years old. He has been taking drugs like syndopa plus, ropark and amantrel. Of late he gets hallucinations. Doctor advised to stop the tablets of ropark and amantrel – but still the illusions persist. If we disagree saying that there is no one inside the room, he gets very angry. Please advise.

- G. S. Prakash Rao

Hallucinations are known to occur in about 20-30% of PD patients who are on anti PD drugs. Almost all the anti PD drugs are known to cause hallucinations. Your doctor has correctly advised to stop the non-levodopa drugs like ropinirole and amantidine. If hallucinations still persist, then the dose of levopdopa would also need to be reduced. Often we cannot reduce levodopa significantly as this leads to worsening of stiffness and slowness of movement. In that case, your doctor will probably prescribe one of the newer, atypical antipsychotic drugs like quetiapine and risperidone.

Sometimes, hallucinations may be the first sign of dementia like alzheimer's disease or diffuse lewy body disease – this will also be needed to be considered by your doctor.

'Patch' those 'Off' Periods and Stop the 'On' Dance

A patch that delivers a drug, in this case rotigotine through the skin may reduce the fluctuating symptoms that are the bane of many people with Parkinson's disease, according to Dr. Peter A. LeWitt. He was speaking at the Movement Disorders Society's Seventh International Congress of Parkinson's Disease and Movement Disorders held in Miami.

Patients with Parkinson's disease and their medical professionals want a continuous effect from medication. Current therapies don't provide this, and the pulsatile effect that they live with now is responsible for the fluctuations in their symptoms.

Because of its 'short acting' property, patients with Parkinson's disease are compelled to take several daily doses of the mainstay medication, levodopa. The effects of this medication are seen in intermittent or pulsatile bursts. Studies on the rotigotine patch were designed to see if it would achieve continuous dosing and bring patients greater symptomatic relief.

Rotigotine belongs to a class of drugs called dopamine agonists (similar to ropinirole and bromocriptine), which are used in the treatment of Parkinson's disease to enhance the effect of levodopa. They can also be used alone, as they mimic dopamine. The quest has been to find out whether these drugs can be absorbed throughout the body through a transdermal patch—a drug delivery system that is worn on the skin, typically the forearm, and releases a drug continuously. Le Witt and his colleagues think that continuous delivery of this drug could address several issues in the management of Parkinson's disease that are neglected by current treatment, primarily a shortened response time after taking medication.

Because patients with Parkinson's disease can experience slowed digestion, **taking drugs orally can be less effective because of problems with**

absorption in the stomach and other parts of the gastrointestinal tract. Transdermal delivery avoids this problem.

The patch could be an **alternative for multiple daily oral doses of medication**, and it may be more tolerable for patients who have adverse reactions such as involuntary movements and hallucinations with medication when the drug reaches its peak effect.

Earlier clinical trials indicate that rotigotine has the potential to address these issues. One study involving 383 patients showed a reduced "off" time, with patients returning to their pre-rotigotine treatment "off" times, when the patch was removed.

Another study involved 329 patients and focused on **reduction of involuntary movements**. In that study the investigators found that the **patch avoided peak-effect problems**.

"The transdermal patch has been tested in both newly diagnosed Parkinson's disease patients and those with advanced disease who have fluctuating symptoms," Dr. LeWitt told Reuters Health. "Recent trials show that it is associated with improved symptomatic relief and increases the 'on' time. These findings are consistent with earlier studies.

(Research on rotigotine has been sponsored by Schwarz Pharma, the drug's manufacturer.

Adapted from : Reuters UK

http://reuters.com/news_article.jhtml?type=healthnews&StoryID=172361

Patch May Provide Steady Dose of Parkinson's Med

November 12, 2002 01:28 PM ET

By Paula Moyer)

Coping with Parkinson's Disease

- G. S. Kohli

The first step is **knowing the nature and scope of this affliction**. The second step, the **treatments and therapies available to assist in dealing with this chronic, but very treatable illness**. The third step is perhaps the most important for the patient. It sets out **what he, assisted by family, friends, treatment team and support agencies, can do to help himself**. A patient's independence and the ability to exercise some control over activities, is an extremely valuable asset not only to the patient, but also to those around them. **This is attainable**. The first two steps will be dealt with in parts, in detail under a regular feature 'Coping Strategy', in *MOVEMENT*, wherein common problems of the 'Young Onset' Parkinsonians and Others and tips to overcome them will be discussed.

Chronic disabilities of movement, such as Parkinsonian's, with their slowness, tremor and multiple others can be tough, depressing and demoralizing for the patient and family. **Patients must struggle with the self-image problems of having the illness, their loss of independence in work and recreation and all of the small nuisances that develop over the years of the illness. Loved ones suffer part of this with the patient, over and above the upsetting of seeing a parent or partner disabled, the feelings of inadequacy and guilt that often develop, and the changes in their own lives that are required to look after the patient.** To handle all this requires insight, an understanding, positive attitude and a unified effort by the patient, friends, family and treatment team.

The reduced facial expression, that is part of Parkinson's, often makes it difficult to interpret a patient's emotional responses. Patients and those interacting with them, should be aware of this. Patients should make people aware of their feelings and try to compensate for this. **Those talking to patients should realize that this is not always a sign of sadness or depression and that the patient may really be very interested in, or find humorous, the story being told.**

When in public, patients are concerned about what others will think of them. **This and other stressful social situations will increase rigidity or tremor and may be improved with counseling, stress management sessions and relaxation therapy.** Caregivers will also benefit from these psychological therapies. **Knowledge and understanding of the disability and its complications will help the patient and caregiver cope with day-to-day trials. PDMS and its affiliated support groups like MPDSG can be of major benefit in providing information, understanding, advice and positive feed-back.**

Tips for the Patient

- **H**andle one day at a time.
- **D**on't dwell on the long-term outlook of the illness.
- **E**ducate yourself and learn as much as possible about the disability, progression, treatment and research.
- **T**ry to be as independent as possible.
- **B**e cheerful and optimistic.
- **F**ocus on and make the most of small benefits.
- **T**hank those who are looking after you frequently. They are not having much fun either and your gratitude will help them cope.
- **P**hysiotherapy and speech therapy may help in adapting to, and improving, certain aspects of the disability.
- **O**ccupational therapy can be useful in assessing the home for use of aids such as hand rails in the bathroom, aids in the kitchen or other assistive devices.
- **L**earn to delegate your responsibilities if you are unable to accomplish them or find them frustrating.
- **R**emain active. Your body will tell you if the activity is stressful and if a less stressful activity is necessary. Exercise will help you maintain your level of function.
- **M**aintain your social life even if it becomes more limited or if new activities are needed.

- **T**ry to overcome feelings of embarrassment when with others or when in public. Admit to having a problem. People will respond to your own secure self-image. Remember many well people are very uncomfortable with illness. Your attitude can influence them.
- **P**atients with a positive attitude do better and so do their caregivers.
- **M**ention and seek help and advice without reluctance for even the small things that are bothering you.
- **M**ake use of the facilities in the neighborhood including home care, outside meals, visiting nurses and transportation.
- **C**aregivers must keep time aside for themselves. Develop outside interests and hobbies.
- **P**lan time together on a mutual activity you both enjoy, like the theatre or walks.
- **A**ttending Support Group meetings may help to discuss common problems and feelings with others who are in the same circumstances. It is also a good place to meet new friends with similar interests and activities.
- **G**o with the patient for medical and other appointments. This can be a great way to gain information, express your concerns and make treatment suggestions. However, do not speak for the patient, if the patient is able to communicate on his own.

Tips for the Caregiver

- **B**e cheerful and optimistic.
- **T**ry to keep life as normal as possible but recognize that you may have to adjust your lifestyle to allow enough time for the patient's activities.
- **R**ecognize that the patient's problems are real and may change from hour to hour. The frequent changes are part of Parkinson's and its drug treatment.
- **P**ut yourself in the patient's position for a better understanding.
- **P**oor memory and confusion are often part of the disability and are made worse by many anti-parkinsonian and other drugs.
- **P**ast emotional problems and anxieties may become worse.
- **C**ounseling and emotional care is available.
- **D**epression occurs in 40% of parkinsonian patients.
- **"You look great"** or **"you look better today"** is very inspiring and believable from someone close.
- **U**nderplaying the illness and its severity is an important method for the patient to cope with the affliction.
- **Y**ou will be better and more able to cope if you have some ongoing relief help in the home and if your loved one has some time in respite care. Holidays for the caregiver are encouraged.

It is indeed important to ensure that the lesser, and easily passed over nuisance problems of Parkinson's are attended to. Something positive and helpful should come out of every physician or clinic visit and this **'doing something'** approach can be a **great comfort and morale booster** for the patient. Patients will do better and be more comfortable with their illness if they have **hope**. **The best strategies to enhance hope are :** the relationship between the patient and treatment team is a partnership, there is an open sharing of information and the emphasis is on **potential** rather than on **limitations**. **The patient will greatly benefit if each visit gives them feelings of :** concern, warmth and caring, problems have been listened to, the treatment plan is clear and help and advice are available.

All the above will go a long way for the patient to have a "near full life in a slightly slow lane".

GOD BLESS !

(Adapted from : Parkinson's – One Step At A Time, - J. David Grimes, Peggy A. Gray & Kelly Grimes Ohman. Pub. Creative Bound Inc.)

Driving With Parkinson's Disease

– Issue of Caution

For most people, driving represents freedom, control and competence. Driving enables most people to get to the places they want or need to go. For many people, driving is important economically – some drive as part of their job or to get to and from work.

Driving is a complex skill. Our ability to drive safely can be challenged by changes in our physical, emotional and mental condition. You and your health-care professional must know how & how much Parkinson's may affect your ability to drive safely.

DRIVING SAFETY IN PARKINSON'S DISEASE

In this study, 39 patients with PD and 25 control subjects without neurologic disease completed testing in a driving simulator. **PD patients had more total collisions on the driving simulator than control subjects**. In PD patients, collisions were associated with Hoehn and Yahr stage and correlated with Unified Parkinson's Disease Rating Scale score (PD disability rating scales).

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How can Parkinson's disease affect my driving ?

Parkinson's disease can cause your arms, hands, or legs to shake – even when you are relaxed. It also can make it harder for you to keep your balance, or start to move when you have been still. If you have Parkinson's and try to drive, you may not be able to:

- **react quickly to avoid a crash**
- **turn the steering wheel**

- **apply the gas pedal or push down the brake**

Can I still, drive with Parkinson's ?

Most likely, “Yes”, in the early stages of the disease, and if you take certain medicines.

What can I do when Parkinson's disease affects my driving?

Ask your doctor about medicines and surgeries that could help treat your symptoms of Parkinson's disease (not particularly specific to **Driving**). Ask about the affect any medicines may have on your continued ability to drive safely.

Staying fit and active will help maintain your muscle strength that you need to drive. This will help keep you safely behind the wheel and on the road.

Your doctor can also refer you to a center or a specialist who can give you on and off-road tests to see if and how your Parkinson's is affecting your driving. The specialist may also advise training to improve your driving skills if your Parkinson's still allows you to drive safely. Improving your skills could help keep you and others around you safe. You can also call your local hospital and rehabilitation facility to find an occupational therapist who can help with the driving skills assessment.

For how many years after diagnosis of PD will I be able to drive ?

This will vary from patient to patient, depending on how well your PD symptoms have been controlled over the years. I, for example rode a motor-cycle till about 12 years after my PD diagnosis, and still drive a car after 22 years without any modifications to the vehicle. **However, neither I nor the Regional Transport Authority (R.T.O.) will recommend your riding a two wheeler after diagnosis.**

What if I have to cut back or give up driving ?

You can keep your independence even if you have to cut back or give up on your driving. It may take planning ahead on your part, but it will get you to the places you want to go and the people you want to see.

Consider :

- **rides with family and friends,**
- **taxi cabs, auto rickshaws,**
- **shuttle and public buses,**
- **trains and state transport buses.**

If you can STILL DRIVE SAFELY and DO, observe the following MUST DOs :

- **Obtain a “Disability Certificate”, which must state that you are fit to drive with or without modifications to the vehicle.**
- Always carry this certificate with you in the vehicle.
- Obtain permission to drive from the R.T.O., who will endorse your driver’s license.
- The front and back of your vehicle must have the ‘HANDICAPPED’ sign.

- Inform your Insurance company about your handicap ; you will get a **rebate on the annual premium payable** by you.
- Explore the possibility of **Modifying your vehicle :**
 - **Power steering**
 - **Auto transmission**
 - **Steering knob for single hand control**
 - **Other driving controls depending on disability, e.g., left or right**
 - **Swivel driving seat for easy entry & exit**

The “Disability Certificate” is very useful even if you do not drive, as it entitles you to a number of concessions on travel by rail, state transport buses & local buses. Apart from this, some facilities like boarding the bus from the front exit and using the handicapped compartment in trains are also available.

IN ANY CASE always wear your safety belt when you are driving or riding in a car. Make sure that every person who is riding with you also is buckled up. Wear your safety belt even if your car has air bags.

The Quest

- A Question of Answers

Does Parkinson’s disease aggravate the blood and urine sugar level in a diabetic patient and increase the risk to life of the patient?

- Anil Dadkar

Diabetes and Parkinson’s disease are not related in any way. Parkinson’s disease and PD drugs do not affect blood sugar levels of a diabetic patient. Diabetes is a major risk factor for heart attacks and strokes but having PD does not directly increase the risk to life of such patients.

Why does the disease go on increasing despite medication?

- D. V. Parekh

This is because the medicines we take only control the various symptoms of Parkinsons like tremor or stiffness or slowness of movement. They do not, as yet, cure the disease itself. Hopefully, in the near

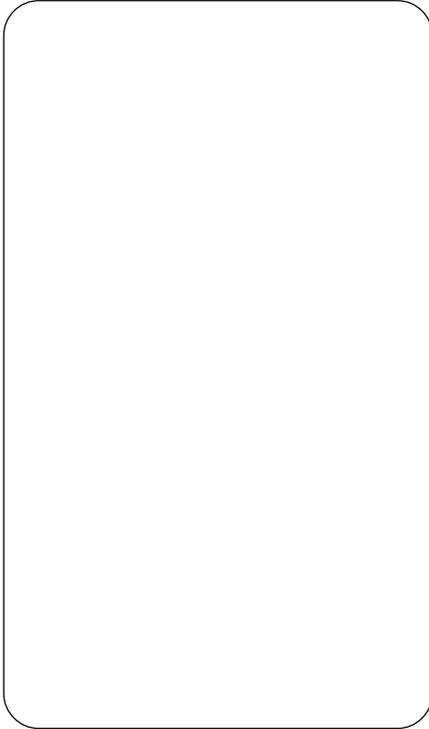
future, there will be treatments found to slow down or stop the worsening of this disease (neuroprotection therapy).

My Parkinson’s disease is not worsening since the last 3 ½ years; but there is increasing depression. Please comment.

- Saroj N. Doshi

Depression is common in PD, being present in nearly 40% of patients. It sometimes can start even before PD is diagnosed. Depression and anxiety significantly affect the quality of life and hence must be properly treated.

Counseling, yoga, physiotherapy and support group help can be very rewarding. You must consult your neurologist regarding antidepressant medications. They can help significantly in improving daily life activities. Antidepressants should be taken regularly for a prolonged period.



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The ball is in your court & we would like it returned. Tell us your views on the contents of this update. Also tell us what you want from *MOVEMENT* You are invited to write to us your comments & suggestions (for details, refer pg. 1, 'Inside This Update').

So, let your response flow.

Moved Recently ?

To ensure you don't miss an update of *MOVEMENT* inform us of your changed address & phone number.

Help make the PD world smaller

Any support group or organization in India or overseas associated with the causes of Parkinson's disease or other movement disorders can write for enrolment in our mailing list free of charge. Likewise, we request enrolment in your mailing list. I'm sure that such interaction will help make this world smaller, & us closer.

Help and Money go Hand in Hand

PDMDS is a 'Charity Society' formed with the main objective of improving the care and treatment of the afflicted and to disseminate knowledge amongst the medical community, public, patients and caretakers. Unfortunately, help and money go hand in hand. Help make life a little easier for the patient. And no amount is too small; every bit makes a difference. Your generous donation may be sent by a crossed cheque in favor of 'Parkinson's Disease and Movement Disorder Society', at its registered office at :

6, Jasville,
1ST Floor, Opp. Liberty Cinema,
Marine Lines, Mumbai – 400 020.

All donations made to the PDMDS qualify for a deduction from your income under the Income – Tax Act. Thank you.