



# movement

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

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## SUPPORT...in its Essence

Jyoti Ghanshani  
Clinical Psychologist

Some things tug at our heart strings at sometime or another and leave a mark there. One such recent incident that has stayed in my mind is when recently at our Borivili support group we planned a meeting just for the caregivers. We however, weren't able to keep the patient members from coming to the meeting. One of them said to me, "We're sorry, but you know we're like family to each other now so we just can't stay without coming here". Well, no apologies required!



Picture Perfect - Borivili Support group  
at the Umargaon Picnic

While we were able to get the required information from the Caregivers, we conceded one fact – the essence of our support group was firmly established

in SUPPORT; in its truest, most pure sense. Support, as we have all experienced in our lives isn't necessarily only in supportive acts but largely in the intangible sense of companionship and sharing that one can only feel. This we have learnt over the course of 4 years of running support groups for our member

patients and caregivers across Mumbai. So, what exactly are support groups then?

A support group is a gathering of people- who all have a thread of some similar

experience running through them. Such groups meet informally to share experiences, exchange information, approach problems with solutions, and most of all- interact on an even and

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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.

### *movement*

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## From the editor's desk



Ever since the 'birth' of this news-letter, I have observed that readers are writing back about progressively more complex & technical issues. This means one, that readers are taking a lot more interest in the intricacies of movement disorders and the management of their symptoms, & two,(therefore) I need to know my onions like the back of my hand.

This issue covers some important medical manifestations of movement disorders. Apart from this, some recently concluded encouraging events have been reported, including an over-night picnic for both patient & caregiver.

As you will appreciate, problems & their solutions amongst 'Young Onset' patients are quite different from those who encounter PD some what later in life. In the former, financial constraints usually also exist, making life a little more difficult. However, even if that is not the case, don't sleep over it with contentment. Know the Law of the Land. I slept over many matters for several years till one morning I found

myself staring at a cheque I had issued for a payment, returned unpaid because my signature on it failed to match

the one given by me to my bank several years ago. Are you aware that being a 'Joint Shareholder' is not the same as a 'Joint Accountholder' with 'either or survivor' instruction? Is it possible for a patient to gift away property at a time when he is hardly able to sign? If you have similar questions to ask, feel free to contact me.

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.

Remember, you're never alone.



*continued from page 1...*

understanding footing. Thus the support that the group lends each one is; Practical, by way of problem solving, information exchange etc, as well as Emotional, by way of empathizing and relating with each other's distress.

Parkinson's Disease and Movement Disorder Society organizes regular support group meetings for its patient and caregiver members across Mumbai.

The support groups gather at regular intervals, usually monthly or 3 monthly intervals. Over the course of each meeting, the gathering indulges in different activities ranging from discussions to demonstrations. While different professionals are invited to lecture on the multidisciplinary approach to treatment and coping with PD, the members of the group contribute richly to

the discussion by relating their experiences with their difficulties and their successes with various problem solutions. The friendly exchange over a cup of tea, about the happenings in each others lives, observations of each other or the

practical tips that are exchanged with the group is what makes the meetings come alive!

Such livewire interaction at our group meetings was what immediately popped in my head while watching a dialogue from a popular recent film, Delhi 6; "India works, the People make it work". This dialogue clearly and truly applies to the support group. It's the people in the group, their dynamics, their exchange, the

therefore has its 'Initiators', the ones who began the group and have been part of it ever since. They believed in the need for such a group and its ability to help others and thereby invited and motivated others to join in. The 'Executors', the ones who envision ideas and execute them. They take it upon themselves to mobilize the group. And of course, the 'Pillars of Strength', who silently but surely ensure that no one in the group is ever alone.



### Engrossed in a Discussion - Khar Support Group

flavor that each individual brings to the congregation that makes the meetings what they are.

The support group has each one essaying a role, albeit a role that they choose. Each support group

The remarkable manner in which the support groups have shaped has been possible because the participants enjoy the experience and relate to it. They thus take on an ownership for the group they belong to, contributing their ideas

to it and taking onus for the satisfactory execution of each meeting upon themselves. Thus also ensuring their presence and whole-hearted participation.

It has been incredible to see the dynamics within the group operate and interact to bear some wonderful results. Some such have been; stage performances by the groups both musical and dramatic, group picnics for a day as well as to overnight locations, organizing therapy and yoga classes for smaller groups, organizing speakers from within their acquaintances to address the meetings, organizing locations or additional demonstrations and sessions. We often speak with great pride of how some of the programs we have developed, such as the Quality of Life-8 session program, and the researches we undertake, such as the Need analysis of homebound patients with PD, have their roots in some discussion or feedback we have received from our support group meetings.

Having read about such groups would have stimulated the interest in many to join such a group. That interest however, often competes with the recurring thought of 'But, will it be helpful to me?' Consider

some questions one could ask oneself to arrive at the answer to that original question- 'How would it be to share my experiences with others and learn from those of others?', 'Would I like to learn more about PD through different people, both patients and professionals?', 'Would I like to interact with professionals on an informal platform to get answers to some of my queries?', 'Would I enjoy helping and supporting others with what I have learnt?'. Consider these ideas along with the prospect of gaining friends for a lifetime who understand what you are going through and are in a position to advise you and support you, and you will find a readiness charging within you to join or start

a support group now!

You could find a support group close to you and enlist yourself there. The schedule for our support groups in Mumbai is given below. Should you find that such a group does not exist in your location and for those from other cities, kindly contact us. We would be happy to help you set up support groups closer to you.

In conclusion we would like to express our appreciation for our support groups and its members. It is in the coming together of each individual member that the essence of our support groups is nurtured.

We thank you all!

Support Groups in Mumbai:	
Borivali (W), S V Road	First Saturday of every month, 10 am
Khar- Santacruz, Linking Road	First Saturday of every month, 4 pm
Marine Lines, Near Liberty Cinema	Last Saturday of every month, 11 am
Ghatkopar/Chembur	Upcoming
Dadar, Portugese Church	Upcoming
P D Hinduja National Hospital, Mahim	3 Monthly
Nair Hospital, Mumbai Central	3 monthly



# Asia Pacific Parkinson's Association (APPA)

Dr. Maria Barretto

The Asia Pacific Parkinson's Association (APPA) was formed in 1997 with the primary objective to foster international collaboration in the Asia-Pacific region to educate the public and the health care professionals about Parkinson's disease and its management, to promote public awareness and to enhance community care in Parkinson's Disease. Biennial Symposiums have so far been held in Kuala Lumpur, Tokyo, Hong Kong, Seoul, Melbourne and Singapore.

The 7th International Symposium of the Asia Pacific Parkinson's Association (APPA) and the 2nd Asian and Oceanian Parkinson's Disease and Movement Disorders Congress (AOPMC) was held in New Delhi from the 15th to 17th February. It was hosted by the Department of Neurology, All India Institute of Medical Sciences (AIIMS).

Prof Madhuri Behari, Head, Department of Neurology (AIIMS) was the Chairperson of the Organizing committee. The event was inaugurated by Mrs. Kiran Walia, Minister for Health & Family Welfare.



Dr. Madhuri Behari, Dr. B. S. Singhal, Dr. Sumit Singh, Dr. Robert Iansek, Hon. Minister for Health & Family Welfare, Mrs. Kiran Walia, Dr. Vinay Goyal

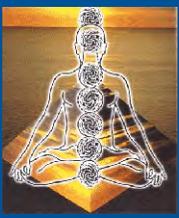
Ms. Mary Baker (European Parkinson's Disease Association) in her address highlighted the significant role of informed patient groups, who through their innovative ideas and projects could create opportunities to partner with

clinicians and the industry to make appropriate responses to their needs.

The Symposium created awareness and addressed the key issues in the management of Parkinson's disease from the perspective of people with

Parkinson's, caregiver, clinician and the researcher. People with Parkinson's had the opportunity to interact with global specialists. It also provided them with an opportunity to educate themselves, through the interactive lectures and workshops conducted on the various aspects of the disease.

The symposium was an enriching learning experience for all the participants who came together in the belief that sharing and learning from one another would bring relief, hope and better care for people living with Parkinson's.



# PDMDS and Iyengar Yoga :

## A Fruitful collaboration

Dr. Rajvi Mehta

The Parkinson Disease and Movement Disorder Society (PDMDS) has been having a fruitful collaboration with Iyengar Yoga through the Light on Yoga Research Trust (LOYRT) since 2005. We have conducted regular yoga sessions which have benefitted over 120 patients, talks during the support group meetings and very recently organised a scientific conference.

On October 12, 2008, PDMDS and LOYRT organised an international conference on 'scientific evidence on the therapeutic efficacy of Iyengar Yoga' at the Bombay Hospital in collaboration with the Bombay Hospital Trust and the Indian Medical Association. This conference was attended by 200 delegates from various medical

specialities with international speakers from reputed universities like University of Essen, Germany and University of California, Los Angeles.

individuals overcome their disorders. And, it is this oral or written sharing of experiences which has led many to take to yoga for its therapeutic applications. But, modern day scientific research and



Yogacharya B K S Iyengar with Dr. Rajvi Mehta (Light on Yoga Research Trust, India) Ms. Lisa Walford (USA), Dr. Andreas Michalsen (University of Essen, Germany), Dr. Kimberly William (University of Wisconsin, USA), Dr. Subhadra Evans (UCLA, USA), Dr. Maria Barretto (PDMDS, India), Dr. B. S. Singhal (PDMDS, India)

It was one of the rare instances where a group of clinicians, scientists and yoga practitioners and teachers were discussing and speaking on the same platform.

There are now hundreds of anecdotes on how yoga has helped

health care demands evidence. Anecdotal evidence, in the form of case reports, do have a role but albeit that is not sufficient. Scientists, like lawyers, would argue that the representative individual / case could be merely a chance occurrence and not essentially as a result of yoga.

To 'scientifically' prove the efficacy of yoga would demand controlled studies with two or more groups of individuals, selection of the right variables to be studied, selection of the right evaluation methods, critical assessment of the data

generated and then proving using statistical tests that the change, if any, observed in the group of patients practicing yoga is indeed due to yoga and not chance. These tests and assessments may not have much meaning from the perspective of an individual practitioner but is extremely crucial for those in health care especially in this era of evidence-based medicine. And, therefore scientific research on the efficacy of therapeutic yoga is important.

The yoga teachers, the scientists and the medical practitioners all work with the aim of improving the quality of human life. If these three groups can work together then we

can well imagine the results of such collaborations. The aim of this conference was to highlight and present the results of such collaborations existing in different universities and institutions in the world.

Research papers highlighting the results of work done on the efficacy of Iyengar Yoga in alleviating symptoms of stress and cardiovascular risk, paediatric chronic pain, depression and anxiety, chronic low back pain and symptoms of Parkinson's disease were presented, and the limitation and difficulties faced by the researchers discussed. Dr. Maria Baretto of the PDMDS presented

the research findings on the efficacy of Iyengar Yoga on individuals with PD. The study elicited a good response among the delegates of the conference.

The highlight of the conference was Guruji, Yogacharya BKS Iyengar demonstrating and explaining how his art works on representative patient groups which left the audience spell bound. The conference ended with a panel discussion with eminent physicians, scientists and yoga practitioners on how this science can be applied as a complementary therapy on health care. This panel discussion was led by eminent neurologist and one of the strong supporters of PDMDS, Dr. B S Singhal.

A compilation of research papers and abstracts of scientific studies on Iyengar Yoga was also presented to the participants. We hope that this conference which has the support of the Indian Medical Association, the apex medical body in India, would lay a foundation for more research into complimentary forms of medicine so that patients can get the best from all forms of therapy!



Guruji demonstrates on a volunteer



# Cognitive Impairment and Dementia in Parkinson's disease

Dr. Pettarusp Wadia

Parkinson's disease is a progressive neurodegenerative disorder affecting 1 in 100 persons over the age of 60. Most of us know this as a disorder affecting the motor system causing tremors, rigidity (or stiffness), bradykinesia (or slowness) and difficulty walking and maintaining balance. Apart from affecting the motor system Parkinson's disease (PD), can also manifest with non-motor symptoms. It can cause forgetfulness and problems with cognitive functions (memory, judgement, geographic orientation to surroundings etc.) as the disease advances.

Today I will highlight some of features of cognitive impairment in PD, differentiation from Alzheimer's dementia and the implications of cognitive impairment on treatment. What is important to remember is that only 30% of the patients with PD actually have any cognitive symptoms. Of this, not all cognitive symptoms necessarily cause disability.

## History

Historically in James Parkinson's initial essay of 1817 (the first description of Parkinson's disease in the world), he reported that "the

senses and intellect [were] uninjured" in the illness, believing that cognitive impairment was not part of PD. It was only in the early 20th century that reports of cognitive impairment in patients with Parkinson's disease were reported. Even then the cause of this cognitive impairment was debated and many attributed it to aging or atherosclerosis. It took another 40 years before the scientists could demonstrate that the changes on the brain in patients with cognitive impairment and PD included Lewy bodies in the cerebral cortex and areas of the brain not commonly affected in PD.

## Definitions

Parkinson's disease dementia (PD-DEMENTIA) is defined as cognitive impairments involving two or more domains (that include cognitive and motor slowing, executive dysfunction, and impaired memory retrieval) and interfering in his day to day activities. When the person has cognitive impairments beyond that expected for his age and education, that do not interfere significantly in their daily activities we use the term mild cognitive impairment (MCI). Prevalence Cognitive impairment in

PD is estimated to increase with age from 2.7% per year at ages 55 to 64 to 13.7% per year at ages 70 to 79. It is estimated that dementia is seen in 20% to 40% of the patients with PD. PD confers a 2-fold to 6-fold risk of developing dementia compared to control populations. Age, disease duration, lower education and male sex are reported as risk factors for dementia.

## Clinical Features

Impairment of attentional function is early and prominent in patients with PD-dementia. The patients have prominent fluctuations in attention and impairment in vigilance. Patients could have good times when they will be coherent, talk sensibly and appear almost normal. At other times they can be confused, disoriented and incoherent. These fluctuations may be day to day or even several times in the day. Another area of deficit in PD-dementia is executive functions (defined as the ability to plan, organize and perform goal-directed behaviour) normally performed with the help of the frontal lobes of the brain. These deficits involve difficulty planning, solving problems and making the right judgement.

Early and prominent deficits in visuospatial function (inability to recognise surroundings, difficulty reading maps, getting lost in previously familiar surroundings) is another characteristic feature of PD-dementia.

All forms of memory including short term memory and long term memory can be involved in PD-dementia. However, the severity of memory involvement in PD-dementia is less than Alzheimer's dementia. Patients with PD-dementia can also benefit from cues and multiple choices to jog their memory. Language is not commonly affected in PD-dementia either.

PD-dementia is associated with prominent behavioural features and change in personality. Hallucinations (seeing things, hearing voices in the absence of any stimulus), depression, delusions (a fixed false interpretation of auditory or visual stimuli) occur commonly in PD-dementia and also as a side effect of many of the dopaminergic drugs used to treat PD. Apathy (not taking interest in tasks, getting withdrawn) may also be seen in patients in early stages of dementia or cognitive impairment. Thus dementia in PD has wide-ranging clinical effects and often also significantly impacts the caregiver taking care of patients with PD.

### Diagnosis

In patients who have cognitive problems with PD the first step is to determine if these cognitive problems are affecting the day to day activities independent of the difficulties in mobility due to PD, i.e. Is this dementia? Once a dementia syndrome is identified, then the next question pertains to the cause of the dementia. Is this dementia related to PD or is it due to another cause.

Common causes of dementia in the population include Alzheimer's dementia, Vascular dementia, Lewy Body Disease and Fronto-temporal dementia. Many drugs may cause confusion and or memory impairment (which subside if the drug is discontinued). Anticholinergic drugs like pacitane, bexol if used often cause memory impairment and/or confusion. Amantadine, dopamine agonists (like Pramipexole and Ropinirole) may exacerbate confusion and hallucinations and may need to be withdrawn and the patient reassessed. Other reversible causes of dementia would include Vit B12 deficiency, hypothyroidism, a subdural hematoma (a clot in the brain commonly occurring in patients with recurrent falls). Lastly significant underlying depression may also mimic dementia.

The clinical pattern of cognitive impairment, the duration of PD prior to developing dementia would be helpful in deciding if the dementia is due to PD or other causes (reversible or otherwise). In situations where the cause is unclear, testing for thyroid functions, Vit B12 levels, imaging of the brain, neuropsychology testing or an EEG may be requested to try and identify the cause.

### Treatment

In PD-dementia there are deficits in acetylcholine in the brain. Based on this, cholinesterase inhibitors like Donepezil and Rivastigmine have been tried for dementia. Clinical trials have shown improvement in cognitive scores (ADAS COG) in patients with PD-dementia. The common side effects of the drugs include nausea, vomiting, and diarrhoea. Diarrhoea may be severe enough to cause weight loss and may require stopping of the oral medications. For those with intractable gastrointestinal side effect, the launch of the Rivastigmine patch in the United States is welcome news as the risk of these side effects has been lower in those using the patch rather than the tablet.

In patients with predominant behavioural complaints atypical anti-psychotic drugs like Quetiapine and

Clozapine may be required if the symptoms are not controlled on cholinesterase inhibitors alone. What can the caregiver or a family member of a patient with PD-dementia do? When a patient with PD starts developing PD-dementia, it would be wise to first take the patient to your treating neurologist for an assessment. Ensure you make a list of the drugs the patient is taking and also take the tablets with you so that the doctor can make sure the patient is not on any medications which can cause confusion alone. Remember to tell the doctor about

falls the patient may have had, by this you can help rule out reversible causes of cognitive impairment. As a family member, understand the symptoms of patients with dementia. Use cues to help the patient remember things. Understand the disabilities of the patient rather than being impatient and try and make the home safe for the patient to live in. Caregivers for patients with dementia and chronic neurological conditions like Parkinson's disease need a break from taking care of patients with dementia. As a family member try

and see that this is being done periodically.

### Conclusions

Not all patients with Parkinson's disease develop cognitive impairment. When cognitive symptoms present, they are usually seen later in the disease course. Not all cognitive problems in patients with PD are due to PD-Dementia. Some of the drugs used for PD, Vit B12 deficiency, thyroid problems are some of the treatable causes of cognitive impairment.



## Mumbai Marathon - 2009

January, 18th 2009; the morning heralded new beginnings for PDMDS in the Standard Chartered Mumbai Marathon (SCMM). We were participating in the event, that is not new....But our Celebrity representation in the Dream Team, representation in the Half Marathon, and large representation in the Dream Run & Senior Citizens Run is !!

Preparations for the event began as early as July 2008, when we began signing up volunteers to participate in the

event. Our team, consequently made up of people from different



Mr & Mrs.Om Puri.Walking with us in SOLIDARITY...every step of the way

walks of life, connected in different ways to the cause of PD. This was the third year of participation for PDMDS in the event and we made every effort to make it an outstanding experience.

Our final team comprised of; Mr. Om Puri (Indian Cineactor) & Mrs. Nandita Puri representing PDMDS in the Dream Team. Dr B.S. Singhal (Founder Member of the PDMDS and Chairman Elect, Movement Disorder Society –Asian and Oceanic Section) and Mr. T. K. Roy (Vice-President,

Sun Pharma) leading the group of doctors, artists, students and friends in the 7 kilometer Dream Run. Caregivers and their friends participating in the Senior Citizen event.

The marathon serves as a great platform to create awareness in the public about PD and the services PDMDS offers for patients and their families. In order to meet this aim, our entire team of supporters sported PDMDS t-shirts and carried the PDMDS banner. This undoubtedly piqued the interest of several persons in the crowd who enquired about PD and the organization. It gladdened us to see their interest & inclination to learn more about the condition and extend their support towards it. We were also able to generate



PDMDS team 2009: Dr. B.S.Singhal, Mr. .T. K. Roy (Vice- President Sun Pharma) and friends

significant media attention towards the cause of PD.

The marathon has also helped PDMDS raise funds to support its services, particularly the Patient Welfare Fund & the Outreach Program. The outreach program, a new initiative, provides care and support to patients that are restricted within their homes, while the patient welfare fund enables us

to provide financial and medical support to needy patients. On the morning of the marathon, the energy and zest of the team were palpable! Everyone was there to pledge their support to the cause of PD and enjoyed the event immensely. Mr. Om Puri, touched by the show of support he witnessed, commented on the strength within the PDMDS group that has helped us cross each milestone and extend our service to the patients with compassion & genuine concern.

We look forward to returning to the SCMM in 2010 with more passion and excitement and certainly in larger numbers!!

Do contact us, if you would like to join us the following year.

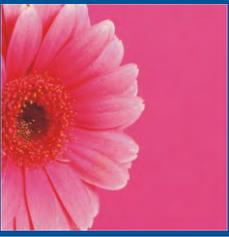


[www.parkinsonssocietyindia.com](http://www.parkinsonssocietyindia.com)

We have recently updated our website, where you will find useful information on all aspects related to Parkinson's disease, its care, other Movement disorders and the work of PDMDS. Some of the topics covered on the website include;

- ◆ What is Parkinson's disease?
- ◆ Treatment of Parkinson's disease
- ◆ Living with Parkinson's disease
- ◆ Yoga & Parkinson's disease
- ◆ Other Movement Disorders
- ◆ Early Onset Parkinson's disease
- ◆ Support Groups for Parkinson's disease
- ◆ Global Perspective on Parkinson's disease
- ◆ Parkinson's disease News
- ◆ Research on Parkinson's disease
- ◆ Resources for the care of Parkinson's disease
- ◆ Common questions on Parkinson's disease

You can also receive regular updates on PDMDS Meetings on the website, Ask your questions to our panel of experts, Share your experiences with others, and Interact with other patients online!



# Managing constipation: A rational Ayurvedic approach

Dr.Namyata Pathak, Dr.Mukesh Shukla  
Smt.K.G.M.P.Ayurveda Hospital, Charni Road, Mumbai-400002

Mr. Aggarwal, a 64 yr old patient of Parkinson's Disease (PD) of about four years, looked visibly depressed. "The isabgol isn't working like it did, doctor. Plus the tremor swings are back." he said. Constipation is an early problem in PD which is persistent and not relieved by dopaminergic drugs. Unfortunately, it may be aggravated by anti-cholinergic drugs which are used for PD management. Let us explore ways to manage this feature from the wisdom available from different sources.

## FIBER, FLUID AND BULK

Fiber rich diet - wholewheat bread, unstrained vegetable juices, chilkewali daal, whole fruits - is the first-line advice for the problem. However, it may be inadequate while patients with swallowing difficulties may not be able to implement it as well. Bulk laxatives like isabgol, which work on the same fiber principle are good but known to cause weight loss on prolonged use. Fibers need adequate fluid intake to work well.

## LIFESTYLE

Exercise and physical activity also keep the gut running. Though

difficult, but constantly challenging our threshold for activity has many added benefits. Yogasanas, like Shalabhasana, Vajrasana and Dhridasana aid the emptying of flatus and faeces. This effect is called 'anulomana' in Ayurveda which is promoted by good digestion. A golden rule for this: Eat only when hungry, upto 3/4th of your stomach capacity. Additionally, ½ tsp Hingvashtaka churna is a digestive which may be had in the middle of a meal. As the formulation contains salt, hypertensive patients should be careful. Also, straining at stools should be avoided as it can cause piles.

## TRIPHALA

Triphala, an Ayurvedic rasayana is also a safe colon brush. It stimulates the appetite, reduces hyperacidity while protecting against anti-oxidant damage. Haritaki, a component of triphala is independently a more potent laxative. Gandharva haritaki is a good combination of castor oil and haritaki. There are some concerns of dependency with prolonged use though.

## OSMOSIS

Epsom salts, Milk of magnesia, lactulose are osmotic laxatives that cause pooling of water to 'flush the gut'. Used when above methods falter, these agents may cause abdominal cramps, bloating and even electrolyte imbalances in patients with reduced renal function. Small doses of Poly-ethylene glycol based solutions have been found to be better than other osmotic laxatives for longer use in PD. These could be discussed with your neurologist.

## THE WHIP

Sonamukhi containing OTC formulations like 'kayam churna' are popular intestinal stimulants. They 'whip the gut' and could be used on a weekly basis. They are known to cause rebound constipation and can paralyze the intestines if used indiscriminately. The fruit pulp of purging cassia (aaragwadha in Sanskrit) soaked in water overnight, may be a safer alternative for a more consistent use.

## OTHERS

Picrorrhiza kurroa or katuki is a liver stimulating, motility promoting herb

which may be used intermittently for 3-4 week phases. Avipattikar churna, Panchasakar churna, samsharkara churna, lavanbhaskar churna are other formulations which may be discussed with an Ayurveda physician before administering as there are individual considerations involved.

### THERAPEUTIC MODALITIES

Biofeedback which is used for constipation in general, could be beneficial in PD. Stimulating the umbilical area by means of 'Nabhi Basti' or Hinga application may be useful. Though there are few trials of any therapeutic modality for

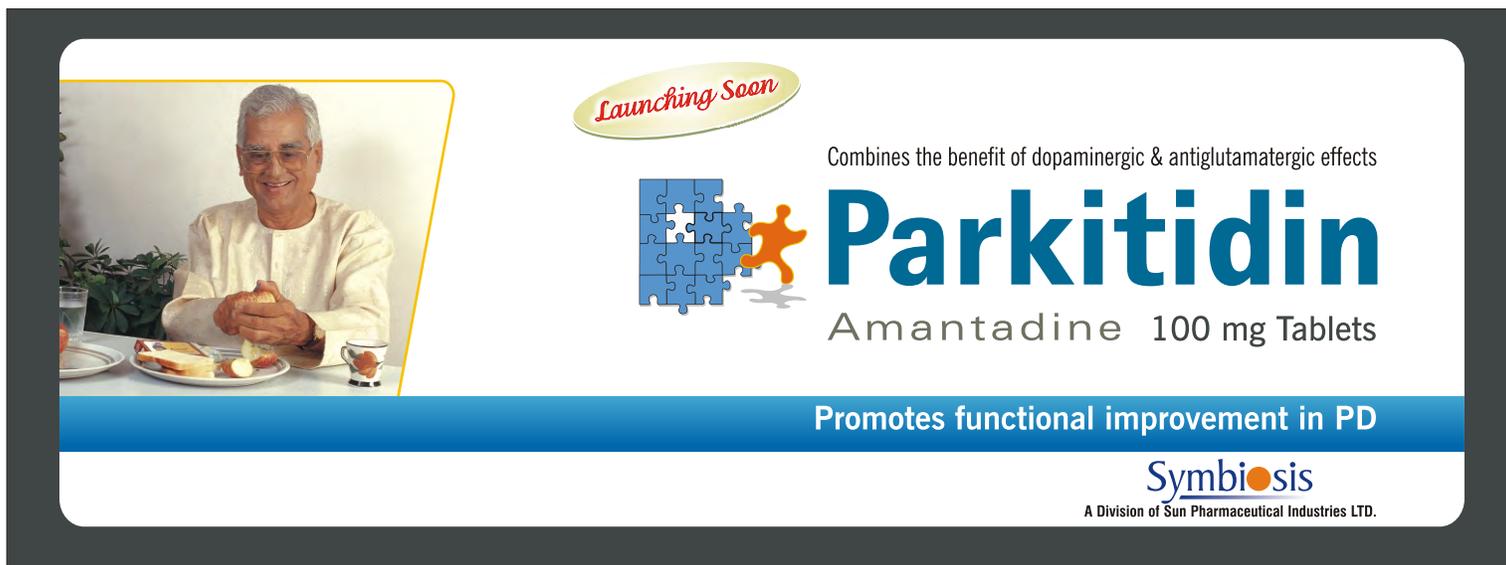
constipation in PD, medicated enemas suggested by Ayurveda show promise. Enemas have a wide range of benefits beyond mere 'colon cleansing'. The gut has an independent nervous system which is now being perceived as a window to the central nervous system. Through this, the enemas may be able to modulate neurotransmitters in the central nervous system.

Also, enemas aid patients whose anal sphincters are dysfunctional; a common cause of constipation in PD. A clinical trial on such an enema - 'Mashadi Taila Basti' is underway at Mittal Ayurveda Hospital, Charni

Road, Mumbai to explore its efficacy.

### IMPACT OF MANAGEMENT OF CONSTIPATION

Mr Agarwal's tremor swing resurfacing could be because reduced gastro-intestinal motility alters L-dopa absorption. Also, mismanagement can promote the silent progression of constipation to impaction, megacolon and perforations. Reduced 'on-off' fluctuations, better nutrition, and the psychological satisfaction following a clean bowel are worth striving for through informed decision making.



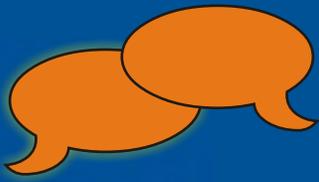
*Launching Soon*

Combines the benefit of dopaminergic & antihypertensive effects

**Parkitidin**  
Amantadine 100 mg Tablets

Promotes functional improvement in PD

**Symbiosis**  
A Division of Sun Pharmaceutical Industries LTD.



# MY STORY

Mr. Vijay Ashar

It was a beautiful sunny evening in Dallas, USA, in October, 2003, after a week of sultry and wet week of raining. We had been visiting our son's family. We had been to a park and our grand children were playing with me while my wife decided to take a walk. I had just retired from a very satisfying career spanning over 37 years in Industry. I was discussing my future plans with my son as I was absolutely fit and bubbling with energy to work for at least another 20 years. My son then pointed out to his mother who was walking briskly in the park and said "dad, mom is equally fit and see the speed with she walks, she would put some one younger to shame. In fact you have slowed down." THOSE WERE PROPHETIC WORDS.

Then during 2005 I accepted another challenging engagement involving lot of presentations and argumentative in nature like that of a lawyer. To my surprise I could have a photographic memory of the legal and commercial matters while figures would not register. To recollect a figure I had to refer back to the relevant file unless that figure was connected to the arguments I

developed. It was then discovered that I could remember primarily those matters which interest me most while the matters of lesser importance normally would not be recorded in the brain. This was to remain with me through life. I finished the engagement in late 2005 and finally decided to call it a day.



My Support System

Then it was December 2006. My wife and I had been to our cardiologist for the annual routine check up. My wife complained to the Doctor, that I had considerably slowed down in my walk and other movements, and also become forgetful. This was the TRIGGER. The doctor wanted me to consult a neurophysician immediately before

he proceeded with the stress test etc. This point onwards it looked as if the world would crumble down around me. What could be wrong with my brain? The neurologist whom I consulted said it was Parkinsonism and there was no cure for the same. While it cannot be cured it can be managed and there were lot of people who were living with it and one can easily consider a reasonable quality of life for 15 to 20 years. He started a regimen of strong medicines, which I could hardly tolerate, but tolerate I did.

One thing of solace was I could drive in the maddening traffic conditions of Bombay and had still split second reactions to avoid any accidents. I started to read and do research on the Internet about the disease. This confirmed the diagnosis and the physical effects, the gradual progression of the disease and how difficult the same could be. I also read about how some people managed the problems so as to lead a useful and working life. What were the latest developments taking place in India and abroad to contain the disease at

a level at which it has damaged the system. The micro surgery performed on a retired lady judge in Jaslok hospital after almost 15 years of post retirement patient living with the disease only on medication and exercise, and who could drive in Bombay.

Then came the saving grace. In April 2007 my GP advised me to consult some senior neurologist and to confirm the prognosis and the medication I had been undergoing. And so began my journey to a new lease of hope and life. While the prognosis was confirmed by my neurologist, his method of treatment was substantially different. I was put on a mild and

smaller dose of some medicines, advised yoga and long walk, exercise, and physiotherapy. I have been following the advise and regular check ups and consultations. In January, 2009 when I went for a scheduled check up, and informed the Doctor that some weakness which I had developed in movements and muscular efforts, have also disappeared and I was feeling over 80 % fit. The secret of my being able to say with confidence that I feel over 80% fit is nothing but a regular work out, exercise, walk regularly for at least 45 minutes a day, take vegetarian diet, lead a regular life from the morning to night, spend time on an activity

which you enjoy and which can challenge your brain (mind games), get involved in some social activity to be of some help to the society in your locality. Not all patients with cognitive impairment due to PD have disability due to the symptoms. For those where the symptoms are affecting the day to day life (PD-Dementia), symptomatic treatments are available, effective and should be sought.

I am sure that “my story” would infuse some hope and confidence in PD affected people and make them live a life of hope and happiness. I shall be glad to be of help to any patient through the good offices of “the Parkinsons Society of India”.



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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:

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