



An update on Parkinson's Disease A session for People with Parkinson's and Caregivers

By Shraddha Kinger

On the 20th of February 2016, the Parkinson's Disease and Movement Disorder Society (PDMDS) had the pleasure of hosting renowned neurologists Prof. (Dr.) Tim Anderson from New Zealand and Prof. (Dr.) Bastiaan Bloem from The Netherlands, as a part of Neurology Foundations' International Neurology Update Conference and the International Parkinson's and Movement Disorder Society's (IPDMS) Ambassador Programme. The programme was held in collaboration with the PDMDS and the Salvation Medical Centre, Our Lady of Salvation Church, Mumbai. Over 250 People with Parkinson's (PwP) and caregiver members of the PDMDS from its 16 support groups across Mumbai attended the programme. The programme focused on two important topics which are pondered upon frequently - New treatments in Parkinson's disease and The non-pharmacological treatment of Parkinson's disease. The day commenced with PwP members of the PDMDS Dadar support centre welcoming the dignitaries warmly with a prayer dance, incorporated from our Dance and Movement Therapy Sessions. The welcome was very graciously received by the guests, after which they were felicitated.

Dr. Tim Anderson first addressed the audience with 'New Treatments in Parkinson's Disease' and elaborated on the caution PwPs and caregivers must exercise when news of a new therapy or drug treatment arises. He discussed briefly varied treatments involving stem-cell therapy and deep brain stimulation among others, but emphasized that all these treatments must not be tried, as the population they are tried on are in no way analogous to ours in terms of sample size.

Dr. Bastiaan Bloem explained the importance of 'Participatory Healthcare' in his talk concerning non-pharmacological treatment of Parkinson's disease. Dr. Bloem spoke of a growing need for the relationship between a doctor and patient to transform from one of an unequal status to that of a team, where the doctor and patient work together towards better health. He asserted that patients are very creative, and know exactly what compensatory mechanisms work for them – with examples of patients with Parkinson's cycling, using laser shoes and creating art in a way that helped their movement.

The audience most appreciated the live translation of this information into Hindi language, by Neurologists Dr. Wadia (Jaslok Hospital, Mumbai) and Dr. Sankhla (P. D. Hinduja Hospital, Mumbai), so that none would lose out on significant information due to language constraints

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The contents of Movement aims to provide the maximum possible facts and information on Parkinsons. This involves some areas of personal judgement; their publication does not mean that the PDMDS necessarily endorses them.

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Dear Friends,

On behalf of the Parkinson's Disease and Movement Disorder Society (PDMDS), it gives me great pleasure to bring you yet another edition of the ever-popular newsletter "Movement."

The entire team of PDMDS led by our dynamic CEO, Dr Maria Barretto, has been actively engaged in numerous activities, events and projects in order to increase public awareness and help improve the quality of life of people with Parkinson's (PD) and their near and dear ones. This issue of the newsletter attempts to give the reader a bird's eye view of some of these important happenings.

Enclosed within is a comprehensive report of a PD support group meeting which was addressed by world renowned neurologists and PD specialists Prof. Tim Anderson from New Zealand and Prof. Bastiaan Bloem from the Netherlands. It was very well attended and the talks and interactions of the experts impressed one and all.

A unique event in which PD patients interacted with children from under resourced communities was facilitated by the PDMDS in November 2015. It was really touching to see how kind and sensitive both the children as well as our patients were in dealing with each other. Do read all the details in this issue.

It gives us great pleasure to inform you that the Parkinson's Society of Nashik was officially registered in December 2015. To commemorate it, Nashik organized its first Unity walk to raise awareness about Parkinson's. Over 300 people participated along with prominent public figures and it received a very good media coverage. Verna has given a graphic account in this newsletter.

As in previous years, the PDMDS participated in the Standard Chartered Mumbai Marathon in January 2016. The distinctive head-gear and other props and banners made the PDMDS conspicuous in the eyes of the public and featured in several newspapers including the Times of India. Kudos to the team and all the volunteers.

On 24th February 2016, the PDMDS organized a fundraising event "Together We Move Better: Shiamak Live". We are truly grateful to the inimitable and divinely talented Shiamak Davar and his dance troupe for putting up this dazzling show for us. Our very own people with Parkinson's also participated and received the maximum applause. You can find the details of this spectacular show in this issue.

As we are all aware, people with Parkinson's are often faced with emotional issues like anxiety, depression, fear and lack of self confidence, which can adversely impact their quality of life. In this issue, we provide the particulars of counseling services, should you desire to avail of them.

As in previous editions where we have experts giving tips and advice on common problems facing PD people, in this issue we have Dr Yasmin Davar writing about the all-important issue of diet and Dr. Preeti Doshi discussing pain issues in Parkinson's Disease. I am sure you will find the articles interesting and useful.

Our dedicated team has been actively involved in community based rehabilitation projects at Dharavi, Wazirpur and other economically and socially compromised regions. Do read about all the selfless work being done at these places. Several other awareness events have also been reported in this issue.

Besides Mumbai, the PDMDS has helped in establishing new centres and support groups in different regions of the country. Gujarat, in particular, has witnessed the growth of several centres in different towns. Please read about the Gujarat story in this newsletter.

I do hope you enjoy reading all that we have compiled. Please do give us your feedback. I wish you all peace and happiness.

- Dr. Jimmy Lalkaka



This was followed by an extremely helpful, interactive Q and A session, where PwPs and caregivers had the opportunity to put forth their queries. Several questions were asked, examples of which included how to manage off-period symptoms, the difference between Progressive Supranuclear Palsy (PSP) and Parkinson's Disease, and questions related to dopamine levels. The dignitaries patiently and



cogently tended to the queries, and were very explicit in their interaction with the PwPs and caregivers.

Finally, some more PwP members of the PDMDS performed a dance showcasing their own Power, to conclude the programme. It was a very fitting end to a day which was patient-centric and encouraged PwPs and caregivers to realize and utilize their power!



World Volunteering Day with Students from the LightHouse Project

By Shraddha Kinger

PDMDS had the pleasure of collaborating with The Lighthouse Project on the occasion of World Volunteering Day. The Lighthouse Project is a not-for-profit in Mumbai that connects working professionals and college students with children from under resourced communities, through one-on-one mentoring in a safe environment. The collaboration was an interesting one, as the objective was to have the students become aware of Parkinson's and also to sensitize them to the changes that occur with the disease. It was a learning experience for our people with Parkinson's as well, who had a great time interacting with and understanding the children better.

On the 21st of November, 15 children aged 12-14 joined our people with Parkinson's at our Support Group session in Byculla. A session was organized to foster inter-generational interaction and sensitivity between both the students and our people with Parkinson's. The students were briefed about Parkinson's disease, after which they had several interesting questions that were answered. The session began with a discussion on "Kindness- An Essential Aspect of Volunteering", through a video. On pairing each student with a person with Parkinson's, both individuals in the pair asked each other some inter-generational questions. These included discussing the barriers and advantages of being their age, their hobbies and their hardships. The children then performed some physiotherapy exercises along with our people with Parkinson's to understand why exercise plays such an integral part in the life of a person with Parkinson's and to live the experience personally.

It was a moving experience to see how patient and sensitive both the kids as well as our people with Parkinson's were in their interactions with each other. The children shared towards the end that the experience was a novel and interesting one, and that they had learned a great deal about Parkinson's in the process. It was a unique experience for our people with Parkinson's as well, as the session ended with both the students and people with Parkinson's writing a message for each other.



UNITY WALK IN NASHIK

By Verna Quadras

2015 has been a milestone year for PDMDS Nashik. Parkinson's Society Nashik (PSN) was officially registered on the 4th of December 2015. Nashik now has four support groups and will be starting its fifth soon. With the gentle persuasion of one of our patients, Mr Kamdar from Mumbai, Nashik dared to have its first Unity walk to raise awareness about Parkinson's on the 5th December 2015.

We had over 300 people taking these first steps with us, patients, educational institutions, Hospitals, doctors, and Senior citizens groups.

The media involved were Radio Mirchi, Lokmat Times and the Times of India. The walk was flagged off at City Center Mall, the biggest shopping area in Nashik by the Senior Police Inspector of Gangapur Police Station Mr Kale, the Assistant Commissioner of Police and head of the Gangapur Police Department. They all joined us for the walk and even felicitated our people with Parkinson's with roses and supportive words. A patient who faltered at the start was put on a wheel chair and thus completed the walk.



A fleet of vehicles followed with patients, police cars and a fully equipped cardiac ambulance with a doctor on board. Flyers were distributed at the mall and along the entire route.

At Thakker's Dome the walk concluded with speeches by the ACP, Police Department, and Neurologist Dr Rahul Baviskar. The co-ordinator, Ms. Verna gave the vote of thanks. The mood was super charged with positivity.

It was truly a great experience for PDMDS Nashik



TOGETHER WE MOVE BETTER – SHIAMAK LIVE



Shiamak Davar and the Shiamak Davar Dance Company presented us, the Parkinson's Disease and Movement Disorder Society the opportunity to tell our story through the artistry of movement and rhythm.

On the 24th of February 2016, "Together We Move Better: Shiamak Live" a fundraising event was organized by us. Shiamak Davar and his dance troupe dazzled the audience of 1200 with their musical dance performances to the jhatkas of Bollywood and to the beats of English numbers. Moreover, our very own people with Parkinson's brought the audience to their feet with a heartrending dance performance proving that nothing is impossible when we all move together towards a cause.

Mr. Shiamak Davar, your kind heart and compassion opened a new door for us with a fundraising and awareness event of this enormity.

This event enabled us to raise awareness about Parkinson's disease and the activities of the society. PDMDS is thankful to all those who attended the show and helped make it a grand success. We are also in gratitude to the following sponsors and donors whose generosity towards this cause facilitated us to extend our services to our beneficiaries.

- ★ Mr. Cyrus Poonawala (Serum Institute of India Ltd.)
- ★ Mrs. Bina Shah & Mr. Harish Shah (Harish & Bina Shah Foundation)
- ★ Mr. Pawan Jain of INOX Air Products Co. for extending their support to sponsor our activities through their CSR programme.
- ★ Our patron Mr. M. B. Parekh and the Parekhs of the Pidilite Industries-your support and ever present sentiment and passion for the cause of Parkinson's is one of the key reasons we continue to forge ahead in our mission. We feel the blessings of Mr. B. K. Parekh upon us through you all.
- ★ Mr. Deepak Parekh (HDFC Bank)
- ★ Mrs. Vijaylaxmi Poddar (Balakrishna Industries)
- ★ Mr. Anand Mahindra (Mahindra & Mahindra)
- ★ Sun Pharmaceuticals Laboratories Ltd.
- ★ Intas Pharmaceuticals Ltd.

We are humbled that the support extended by each of you will help us continue our endeavour of providing care and rehabilitation, and subsequently a better quality of life to people with Parkinson's and their caregivers.

Thank you, for together, we do move better!

STANDARD CHARTERED MUMBAI MARATHON 2016



We thank the following individuals and companies for making our participation in the Standard Chartered Mumbai Marathon 2016 a success:

- | | |
|---|--|
| 1. Mr. Sanjay Agarwal | 6. Blossom Industries Ltd. |
| 2. The Quopn Company Pvt. Ltd. | 7. Subhash Runwal Education Foundation |
| 3. Sunpharma Laboratories Ltd. | 8. Anusuya Air and Sea CLG Agency |
| 4. Rubber Publications Bombay Pvt. Ltd. | 9. Mr Pratik Prakash Pawar |
| 5. Balkrishna Industries Ltd. | |

Counselling *By Bijal Thakker*

At PDMDS, we strive to provide a holistic experience to each and every person with Parkinson's (PwP). We have their complete well being in our minds. Each PwP that comes in, faces his/her set of challenges, along with fighting Parkinson's, which is a common link between all of them.

Over the years we have observed that they have common concerns associated with anxiety, depression, lack of confidence, low motivation, why me? etc. That is where individual counselling comes in.

Through individual counselling we are hoping to help patients accept themselves and their situation, be more positive individuals who can learn to deal with their challenges and adapt to the situations and build on their self confidence.

For Appointments, please call

99872 16057

98212 79697

Timings:

Dadar Centre:

Mondays and Fridays

10.00 a.m. to 1:00 p.m.

Borivali Centre:

Wednesdays

10.00 a.m. to 1:00 p.m.

Nutrition in Parkinson's Disease :

by Yasmin Davar, (BHsc in Nutrition and P. G. Diploma in Dietetics)

Most of us know that Parkinson's disease is a neurological disorder that affects our body movement. The disease progresses slowly and gradually the quality of life is affected. The rate of progression generally varies from person to person and is very individualized. As is the case with most diseases, medication is prescribed to control the progression of the disease.

Nutrition is particularly important in Parkinson's disease for many reasons: the disorder itself slows transition through the gut affecting absorption of the medications and nutrients. These patients may also have other medical problems or diseases that puts them at a greater risk of malnutrition. Poor nutrition can worsen other conditions like diabetes and hypertension which in turn can worsen function in Parkinson's. In addition, good nutrition promotes overall brain health and may have some protective benefits.

Diet and Medication: : Our Indian diet consists of carbohydrates, proteins and fats. Taken on a percentage basis, 60 – 65 % of the calories in our diet should be provided from carbohydrates, 12 – 15 % from proteins and 25 to 30% from fats. The recommended daily allowance of proteins for an Indian adult male is 60 g and for an Indian adult female is 50 g (or 1 g / kg Ideal body weight).

Patients who are just beginning to take Levodopa are often asked to take it with food to decrease the nausea that sometimes results. Later on, as the disease progresses, many patients note that their levodopa does not work as well when taken at or near meal times. This could be so because proteins and levodopa compete for intestinal absorption and transport across the blood brain barrier thus reducing the effectiveness of L dopa. Hence redistributing the intake of proteins in the diet helps to increase the absorption of the drug.

Understanding Our Food: Proteins are present in non-vegetarian foods like egg, chicken, fish and meat.

Vegetarian sources of proteins include milk and milk products like paneer, cheese and all pulses and dals (e.g. chole, rajhna, moong, tuvar). Even carbohydrates (e.g. rice, jowhar, wheat, bread, pohe) contain a small amount of protein. Rice has a lower protein content than wheat and the only foods which do not contain any proteins are sago, arrowroot

What to Eat ? - From the above it is clear that fruits and vegetables may be taken and rice is preferred over chapattis. Hence one may take chapattis made from rice flour along with a vegetable, steamed or boiled rice or a vegetable pulav. Alternatively, sago khichdi (sabudana khichdi) can also be taken with minimum addition of peanuts. All the root vegetables like potatoes, sweet potato & raw banana are high in starch and contain negligible amounts of protein.

Since all non vegetarian foods are high in protein, the quantum or portion size needs to be reduced and taken along with rice, bread or pasta. Mince cutlets may be made with a small quantity of mince and a larger quantity of potatoes. Likewise chicken or fish may be taken in a very small quantity with a generous helping of sautéed vegetables.

Antioxidants and Parkinson's : Besides redistributing the intake of proteins at the time of medication, patients are also advised to increase the intake of antioxidants. Antioxidants are substances that prevent oxidative damage. Oxidative damage is thought to be part of the mechanism of ageing and cell death in some neurodegenerative disorders. Research studies have suggested that a diet rich in antioxidants may help in preventing some of this damage.

Anti oxidants include vitamins such as vitamin A, C, E and substances such as lycopene and polyphenols. Vitamin A is found in vegetarian foods as Beta carotene which is converted to Vitamin A in the body. It is present in yellow orange fruits and vegetables like papaya, red pumpkin, leafy vegetables like spinach, fenugreek and carrots.

Vitamin C on the other hand is present in guavas, strawberries and citrus fruits like oranges, sweetlime, lime and capsicum. Vitamin E can be obtained from nuts, grains and wheat germ.

Lycopene is a red coloured carotenoid present in certain fruits and vegetables. Rich sources of lycopene include tomatoes, guava, watermelon, papaya, grapefruit, carrots, purple cabbage and asparagus.

Polyphenols once again are non-vitamin natural antioxidants. Good sources of non-vitamin natural antioxidants include red wine, berries, grapes, fresh turmeric, sesame seeds and tea. Tea which is one of the most widely consumed beverages in India is rich in polyphenols. Green tea does not undergo a fermentation process during manufacture and contains catechins which are particularly helpful for Parkinson's disease patients.

Constipation: A high intake of fruits and vegetables is also beneficial in overcoming constipation which is a common problem in Parkinson's disease. Try and include as much fibre in the diet as possible. Whenever possible, eat fruits without peeling, a tossed salad, sprouted pulses and oats all of which are high fibre

foods. In place of refined flour (maida), oats may be used to thicken gravies and soups. If chewing the vegetables is a problem due to poor dentition, then puree them, juice them or drink as a soup as all these will to a certain extent help in reducing the constipation. Plenty of other liquids and exercise will also be beneficial.

Orthostatic hypotension: Another condition that people with Parkinson's need to be aware of is orthostatic hypotension. Orthostatic hypotension is a condition in which there is a sharp drop in blood pressure that occurs when a person gets up from the bed or chair causing dizziness or even loss of consciousness. Both Parkinson's and the medication used to treat it may cause this condition. Moreover these patients may also be on certain blood pressure medication. Thus it is necessary for patients to have a basic understanding of orthostatic hypotension, be well hydrated at all times, eat small meals frequently and avoid a sudden change in position.

Thus, in summary it can be said that good nutrition will help to a certain extent in improving the quality of life, which is affected in this neurological disease.



HIGH FIBRE LOW PROTEIN CUTLETS

Ingredients:

½ cup cauliflower (boiled)	coriander leaves - few
1 cup mixed vegetables (carrots, frenchbeans, potato, peas) (boiled)	ginger-garlic paste
½ cup oats	green chili paste
½ cup oat flour (grind in mixer)	garam masala
	oil for frying

Method

Mix the boiled vegetables with the oats and the masalas. Shape into balls and flatten. Coat with oat powder and fry in a non-stick pan using oil as required. Serve hot with green chutney or tomato ketchup.

SKILLET CHICKEN WITH VEGGIES

Ingredients

1 onion (cut into 8 pieces)	30 – 50 g of boneless chicken (boiled)
1 carrot (cut lengthwise)	1 tomato / 4 -5 cherry tomatoes
1 red bell pepper (capsicum cut lengthwise)	1 small piece of ginger
1 small broccoli / cauliflower (cut into florets & boiled)	3 - 4 pods of garlic

Ingredients for the Sauce

1 tsp red chilli flakes	1 tsp lemon juice
½ tsp soy sauce	2 tsp oil / butter
2 - 3 tsp honey	3 - 4 tbsp hot water

Method

Take a little oil in a thick bottomed pan and saute the ginger garlic & onion pieces. Add the boiled chicken and vegetables and stir fry for a while on a low flame. Mix the ingredients for the sauce and add to the chicken vegetable mixture. Cook for 2 – 3 minutes. Serve topped with cherry tomatoes. This dish may be taken along with tomato / spinach soup in place of chicken, tofu or paneer may also be used.

पार्किंसंस में पोषण

- डाक्टर यास्मीन डार

अधिकतर लोगों को जानकारी है कि पार्किंसंस रोग एक तंत्रिका बिमारी है जो हमारे शरीर के हलन चलन को प्रभावित करता है। यह बिमारी धीरे धीरे बढ़ती है और आहिस्ता आहिस्ता इसका असर हमारे जीवन की गुणवत्ता पर पड़ता है। इसके बढ़ने की गति अलग अलग व्यक्तियों में अलग अलग और व्यक्तिगत होती है। जैसे की हर रोग में होता है वैसे ही इस बिमारी की बढ़ोतरी पर काबू पाने के लिए निर्धारित दवाएं दी जाती है।

खास कर इस बिमारी में कई कारणों के लिए पोषण बहुत महत्वपूर्ण है। इस बिमारी के कारण दवाईयाँ पोषक तत्वों के अवशोषण की गति आंत से गुजरते हुए धीमी पड़ जाती है। इससे पीड़ित लोगों को अन्य बिमारीयाँ भी हो सकती है जिसके कारन कुपोषण का बड़ा खत्रा हो सकता है। अगर पोषण की मात्रा सही न हो तो मधुमेह (डायबीटीस) और उच्च रक्त चाप (बी.पी) जैसी अन्य स्थितियाँ खराब हो सकती है जिसका बुरा प्रभाव पार्किंसंस पर पड़ सकता है। लेकिन अच्छा पोषण दिमाग की पूर्ण स्वास्थ्य में सुधार लाता है और जीसके कुछ रक्षात्मक लाभ भी हो सकते है।

आहार और दवा: हमारे भारतीय आहार में कार्बोहाइड्रेट, प्रोटीन और वसा (फैट) होती है। ६०% - ६५% कैलोरीज़ कार्बोहाइड्रेट से प्राप्त होनी चाहिए, १२% - १५% कैलोरीज़ प्रोटीन से और २५% - ३०% फैट से मिलनी चाहिए। एक भारतीय पुरुष की प्रोटीन की दैनिक आवश्यकता है ६० ग्राम और महिला के लिए ५० ग्राम (या १ ग्राम प्रति किलो आदर्श शारीरिक वजन)।

जिन रोगियों ने लीवोडोपा नई - नई लेनी शुरू की है उन्हें कहा जाता है की आहार के साथ उसे ले जिसे जी मिचलना कम हो। जैसे जैसे यह बिमारी बढ़ती जाती है कई पीड़ितों को लगता है की लीवोडोपा का असर भोजन के साथ या भोजन के कुछ समय पूर्व लेने पर भी नहीं होता है। ऐसा इस लिए हो सकता है क्योंकि प्रोटीन और लीवोडोपा आंतों में अवशोषण (अब्जोर्बशन) के लिए और रक्त-मस्तिष्क बाधा पार करने की दौड़ में लगे रहते है जीसके कारन लीवोडोपा का असर कम होने लगता है। इसलिए अगर आहार में प्रोटीन के सेवन का पुनःवितरण किया जाए तो दवा के अवशोषण की बढ़ोतरी में मदद मिल सकती है।

अपने आहार को समझना: मांसाहारी आहार जैसे कि अंडे, मुर्गी, मछली और मांस में प्रोटीन होती है। शाकाहारी पदार्थ जैसे की दूध, पनीर, चीज़, सभी तरह की दालें (उदाहरण चावल, ज्वार, गेहूँ, पाऊँ, पोहे)। चावल में प्रोटीन की मात्रा गेहूँ से कम होती है। परंतु साबूदाना, अरारूट, फल और सरल चीनी ऐसे खाद्य पदार्थ हैं जिनमें प्रोटीन नहीं होता। तब सवाल यह उठता है की हम क्या खाएँ?

क्या खाया जाए?: इन बातों से स्पष्ट है कि फल और सब्जियाँ का सेवन किया जा सकता है और गेहूँ से ज्यादा चावल का सेवन करना चाहिए। इसलिए चावल के आटे से बनी रोटी और साथ में सब्जी, भाँफ दिए हुए या ऊबले चावल या कोइ सब्जी - पुलाव खाना चाहिए। इसके अलावा साबूदाना खिचड़ी जिसमें थोड़ी ही मूँगफली हो उसको खाया जा सकता है। सभी मूल सब्जियाँ जैसे कि आलू, शक्करकण्ड और कच्चे केले में स्टार्च की मात्रा अधिक होती है और इनमें प्रोटीन ना होने के बराबर होता है।

सभी मांसाहारी आहार में प्रोटीन ज्यादा होती है इसलिए लीवोदोपा की दवाई लेते वक्त उनको कम मात्रा में लेना चाहिए और इनके साथ चावल, पाँऊ और पास्ता को भी खाना चाहिए। कीमे के कटलेट (टिक्की) बनाने में कीमा कम और आलू की मात्रा ज्यादा होनी चाहिए। इसी तरह मुर्गी और मछली खाने के साथ बड़ी मात्रा में कम से कम तेल में तली हुई सब्जियाँ खानी चाहिए।

एन्टी - ऑक्सीडेंट और पार्किंसंस: इलाज के दौरान पीड़ितों को प्रोटीन के सेवन के पुनः वितरण के अलावा यह सलाह भी दी जाती है कि वे एन्टी - ऑक्सीडेंट के सेवन की मात्रा बढ़ाएं। एन्टी - ऑक्सीडेंट वे पदार्थ हैं जो ऑक्सीडेटिव नुकसान पर रोक लगाते हैं। माना जाता है कि ऑक्सीडेटिव नुकसान वृद्धावस्था और कुछ न्यूरोदीजेनेरेटिव बीमारियों में कोशिकीय मृत्यु का एक हिस्सा है। अनुसंधान अध्ययन सुझाते हैं कि एन्टी - ऑक्सीडेंट से भरापूरा आहार इस नुकसान पर कुछ हद तक रोक लगा सकता है।

एन्टी - ऑक्सीडेंट में शामिल है विटामिन जैसे कि ए, सी, ई और लाइकोपीन और पॉलीफेनोल्स जैसे पदार्थ। शाकाहारी आहार में विटामिन ए बीताकेरोटीन के रूप में पाया जाता है। पीले और नारंगी फल और सब्जियाँ जैसे कि पपीता, लाल कद्दू, गाजर और पालक, मेथी जैसी पत्तेदार सब्जियाँ में भी पाया जाता है।

अमरुद, स्ट्रॉबेरी और चकोतरा फल जैसे कि संत्रा, मौसंबी और शिम्ला मिर्च में विटामिन सी पाया जाता है। विटामिन ई की प्राप्ति काजू-बदाम आदी, अनाज और गेहूँ से होती है। लाइकोपीन लाल रंग का कैरोटीनॉयड है जो फलों और सब्जियों में पाया जाता है। लाइकोपीन काफी मात्रा में टमाटर, अमरुद, तरबूज, पपीता, चकोतरा, बैंगनी रंग की गोभी और शतावरी में पाया जाता है।

पॉलीफेनोल्स और विटामिन प्राकृतिक एंटी - ऑक्सीडेंट हैं। गैर विटामिन के प्राकृतिक एंटी - ऑक्सीडेंट स्रोत हैं रेड वाइन, जामुन और बेर, अंगूर, ताज़ी हल्दी, तिल और चाय। भारत में सबसे ज्यादा पीये जाने वाला पेय पदार्थ है चाय जिसमें पॉलीफेनोल्स की मात्रा बहुत अधिक रहती है। हरी चाय (ग्रीन टी) को निर्माण के वक्त विक्षोभ (फर्मेन्ट) नहीं किया जाता और उसमें कॉठेचिंस होने की वजह से यह पार्किंसंस से पीड़ितों के लिए बहुत सहायक है।

कब्ज: ज्यादा मात्रा में फल और सब्जियों का सेवन करने से कब्ज पर काबू पाया जा सकता है जो पार्किंसंस से पीड़ित लोगों की एक आम समस्या है। कोशीश कीजिए कि आहार में रेशे (फायबर) की मात्रा ज्यादा हो। हो सके तो फलों को बिना छीले ही खाएं। सलाद, अंकुरित दाल और अनाज, और जई (ओट्स) का सेवन करें क्योंकि इनमें ज्यादा मात्रा में रेशा होता है। कढ़ी या शोरबा को गाढ़ा बनाने के लिए मैदे के बजाय जई का उपयोग करें। दांतों की समस्या के कारण अगर सब्जियाँ चबाने में तकलीफ हो तो उनका रस निकालें या शोरबा कर पीएं जिससे कब्ज की तकलीफ में कुछ राहत मिले। ज्यादा तरल या रसीले पदार्थ और व्यायाम से भी फायदा होता है।

ओर्थोस्टेटिक हाइपोटेंशन: पार्किंसंस से पीड़ित लोगों को एक अन्य स्थिती ओर्थोस्टेटिक हाइपोटेंशन की जानकारी होनी चाहिए। यह वह स्थिती है जिसमें मरीज़ के बिस्तर से या कुर्सी से उठने पर रक्त चाप में तेज गिरावट आती है जिसके कारण चक्कर आते हैं या व्यक्ति बेहोश भी हो सकता है। इसका कारण पार्किंसंस या उसके लिए दी जाने वाली दवाइयाँ भी हो सकती हैं। खासकर ऐसे मरीज रक्त चाप के लिए भी अन्य दवाइयों का प्रयोग करते हैं। इस लिए जरूरी है कि ऐसे मरीजों को ओर्थोस्टेटिक हाइपोटेंशन के बारे में मूलभूत ग्यात हो, वे बराबर पानी पीते रहें, कम मात्रा में पर दिन में अकसर खाना खाएं और झटके से अपनी मुद्रा न बदलें।

संक्षेप में यह कहना उचित रहेगा कि अच्छे पोषण से जीवन की गुणवत्ता में कुछ हद तक सुधार आ सकता है जो पार्किंसंस कारण प्रभावित हुआ है।

उच्च फाइबर (ज्यादा रेशा) कम प्रोटीन कटलेट:

बनाने की सामग्री:

१/२ कप (प्याला) उबली फूलगोभी
१ कप उबली हुई मिश्रित सब्जियाँ
(गाजर, आलू, मटर, फ्रेंच बीन्स-सेमकी फली)
१/३ कप जई
१/२ कप जई का आटा (ग्रायंदर/ मिक्सी में पिसा हुआ)

धनीये के पत्ते
अदरक - लहसून का पेस्ट
हरी मिर्च का पेस्ट
गरम मसाला
तलने के लिए तेल

विधि:

उबली सब्जियों को जई और मसालों के साथ मिला दें।
छोटे छोटे गोले बनाकर कटलेट का आकार देकर जई के आटे में लेप दें।
नॉन स्टिक तवे में जरूरत के हिसाब से तेल गरम कर दें और कटलेट को तल दें।
हरी चटनी या टमाटर की चटनी के साथ गरम परोसे।

PAIN IN PARKINSON'S DISEASE (PD)

By Dr Preeti Doshi (MD, FIPP, FRCA), Consultant Pain Specialist, Jaslok hospital and Research Centre, Mumbai

Pain is one of the non-motor symptoms of PD presenting sometimes even well before the diagnosis of PD is made. In view of the fact that PD is a movement disorder, motor symptoms always predominate, so in spite of its high prevalence, pain remains undiagnosed and undertreated in many patients. Pain in Parkinson's disease has multiple dimensions and characteristics. It is important to understand that pain can be a part of the Parkinson's experience and one should learn ways to manage it. Uncontrolled pain can have several physical ill-effects and in addition can lead to cognitive, behavioural, mood and sleep disturbances which can affect the interpersonal relationships and social activities worsening the quality of life.

Pain can be classified into two main categories:

- a. **Nociceptive** : which relates to tissue damage, implicating the pain receptors in the skin, bones or surrounding tissues;
- b. **Neuropathic** : indicating pain arising in nerves; or as a mixed pain syndrome involving both nociceptive and neuropathic pain.

In Parkinson's, most pain experiences are nociceptive which means it results from activation of terminal nerve endings in the tissue that is injured or has the potential to be damaged. The causes include persistent tremor, muscle rigidity, dystonia, musculoskeletal injury (i.e. sprains, bruises, bone fractures resulting from a fall etc.) and inflammation. Depending on your clinical symptoms and signs your specialist will decide how to address your pain.

In the western population the reported prevalence of pain ranges from 46% to 83 % in patients with Parkinson's disease but figures vary from place to place depending on the inclusion criteria. According to an Indian study the prevalence is about 55% which is roughly 1 out of every two patients with PD. Pain was more pronounced on the side with predominant motor symptoms (72%).

As proposed by literature, Parkinson's Disease results from the death of dopamine-generating cells in the Substantia Nigra, a region of the midbrain. Proper and early treatment of Parkinson's disease may also improve rigidity and increase the range of movements which could probably decrease the incidence of pain.

Why do PD patients get pain and how to recognise and deal with it!

Fortunately, many options exist for treating pain. How can you find which are right for you? The first step is to talk to your doctor who can assess your pain and then help to build a pain management plan. The most important diagnostic tool is the clinical history, which is necessary to identify the type of pain related to PD. Patient should discuss with the treating doctor, all the details about the pain they experience! Now let us look at the evaluation of different types of pain and their management strategies.

1. The pain in PD generally arises due to twisting and writhing movements like rigidity, tremor, akinesia or postural abnormalities in different parts of the body. Muscle cramps or tightness in patients with PD can affect any part of the body but it appears more typically in the neck, arm, para spinal or calf muscles, while joint pain occurs most frequently in shoulder, hip, knee and ankle. The prevalence of musculoskeletal pain ranges from 45% - 74% in those patients with PD experiencing pain. The treatment of musculoskeletal pain in PD can vary depending on the cause. If the pain is due primarily to parkinsonian rigidity, dopaminergic therapy, physical therapy and exercises are indicated.
2. Another variety of pain is **radicular-neuropathic pain** which manifests itself with pain, numbness or weakness in the area of a nerve root as a consequence of nerve or root compression. The prevalence of this is 5-20%. Postural abnormalities

and dystonia developing during the disease can lead to disturbed mechanics in the spine affecting dimensions, joint arthritis and disc protrusion or slipped discs with resultant pressure on nerves resulting in sciatica like pain. Management is multimodal with the help of physiotherapy, drugs and target guided spinal injections performed with X-ray guidance in refractory cases with mild disc protrusions.

3. **Dystonic Spasms** can produce severe pain which may be paroxysmal, spontaneous or triggered by movements or activities involving extremities, the face and the pharyngeal muscles and is prevalent in 8% to 47% patients.
4. **Central Pain** is an insistent pain not restricted to nerve distribution which manifests as neuropathic sensory symptoms such as paraesthesia[tingling/pricking] or shooting pain. The patient usually describes it as a bizarre and unexplained painful sensation predominately on the more affected side and in the "OFF" state. Central pain can occur in different areas of the body including the mouth, chest, abdomen, rectum, vagina and testes. The prevalence of central pain in patients with PD is 10-12%. It responds well to dopaminergic medications but in resistant cases standard neuropathic pain medications and tricyclic anti-depressants may be useful. Occasionally use of opioid drugs may be required in severe pain but have to be used with caution and under supervision of a pain specialist.
5. **Akathisia** is a discomfort sensation used to describe subjective restlessness or the painful impulse to move continually. This pain generally improves with levodopa treatment.
6. **Restless Leg Syndrome (RLS)** is another cause of pain in patients with PD. It is defined as a sensory-motor disturbance that is prominent at night and improves with movement. It includes intense and disagreeable sensations (paraesthesia and dysesthesia) of the extremities, more pronounced in the lower extremities. Prevalence ranges from 8% to 20% in patients with PD which is much higher than in general population [1%].

Factors potentially affecting pain in Parkinson's Disease

1. Gender- Some clinicians have described neck and back pain more prevalent in female patients with PD.

2. Duration and Severity of disease- A longer duration of disease and greater motor complications result in higher incidence of pain in patients with PD according to some clinicians.
3. Scientists have shown that depression, which affects approximately 40 percent of individuals diagnosed with Parkinson's, plays an important role in the way people perceive pain. Similarly, tension and muscle stress caused by anxiety can compound pain. Current evidence suggests that depression can modify the perception of pain and it is treatable.
4. Patients with pre-existing pain related to systemic diseases such as diabetes, osteoporosis, rheumatic disease and age-dependent [e.g. joint or disc disease] or postural problems will continue to experience pre-existing pain after diagnosis which may potentially worsen due to PD features such as rigidity, akinesia, muscular cramps and postural instability.
5. A person who pays more attention to his or her pain and reacts to pain with a high level of stress will likely experience more pain than someone who tries to ignore the pain and considers it irrelevant to his or her daily life. Feeling helpless to control pain that is, believing that pain is uncontrollable or that there are not treatment options or health professionals available to assist in managing pain can also make pain seem worse.

Pain is a significant problem in PD patients at all stages with specific problems depending on duration of the disease. Dystonia and dyskinesia related pain sets in later stages of the disease. Pain clearly affects the quality of life (QOL) of PD patients.

Since pain and sensory symptoms in PD represent a broad spectrum, a multidisciplinary approach to pain management is recommended. Nevertheless, it has been found that 50% of patients with PD-related pain did not receive any treatment. The treatment is based on specific type of pain diagnosed after thorough assessment regarding the type of pain. It is important to note that one size does not fit all!

TREATMENT & REHABILITATION

Management options for pain in Parkinson's include both the pharmacological (i.e., medications) and the non-pharmacological. A combination of both may offer the best pain control, and an interdisciplinary model of care can lead to optimal results for pain management.

Some common treatment options include:

- Medications-Analgesics and Adjuvant drugs
- Physical therapy
- Massage
- Botulin toxin injections
- Nutrition management
- Exercise
- Acupuncture/Acupressure
- Psychotherapy/Cognitive Behavioural therapies
- Yoga/Stretching/Meditation
- Group therapy
- Minimally invasive pain blocks -These may be considered in select patients who fail to respond to simpler measures. These are performed under local anaesthesia using X-ray guidance to deliver the medication precisely on the target.

An individualised approach helps achieve the best possible control of pain. Regular reassessment may help to modify treatment as needed.

Conclusion:

Pain features as an important non-motor symptom in patients with Parkinson's disease. It being

subjective in nature remains underdiagnosed and undertreated. It is important to address pain because it may interfere with day-to-day activities, mood, sleep and overall enjoyment of life. Specific problems resulting from chronic pain may include sleep disturbance, malnutrition, social withdrawal, physical and functional decline, depression, anxiety and impaired cognition. Pain also accounts for increased overall health care costs. In practical terms, it often proves helpful to conceptualize the experience of pain in Parkinson's as relating to one or more of the following five categories: pain from the muscles or skeleton, pain from nerves or spinal roots, pain related to sustained twisting or writhing, discomfort from akathisia and pain caused directly by changes in chemicals in the brain due to PD.

Proper and early treatment of Parkinson's disease may also improve rigidity and increase the range of movements which could probably decrease the incidence of pain. Management should involve an individualised patient based assessment with suitable multimodal approach to achieve the best possible control of pain.



पार्किंसंस में दर्द

- डॉ. प्रीती दोषी,

एम.डी, एफ.आई.पी.पी., एफ.आर.सी.ए.- दर्द विशेषज्ञ सलाहकार, जसलोक रंगनालय और संशोधन केंद्र

पार्किंसंस में दर्द एक गैर-मोटर लक्षण है जो कभी-कभी पार्किंसंस के निदान से पहले ही हाज़िर होता है। यह ध्यान में रखना है कि पार्किंसंस गतिविधियों का विकार है, इस लिये मोटर लक्षण हमेशा प्रबल होते हैं। इसकी वजह से भलेही दर्द का प्रसार उच्च हो पर दर्द का निदान नहीं हो पाता और कई मरिज़ अनुपचारित रह जाते हैं।

पार्किंसंस में दर्द के एकाधिक आयाम और विशेषताएँ हैं। यह जान लेना और समझ लेना ज़रूरी है कि दर्द पार्किंसंस के अनुभव का एक हिस्सा है और इसलिए इस के साथ कैसे प्रबंध निभाया जाए यह सिखना ज़रूरी है। अनियंत्रित दर्द के कारण शरीर पर कई प्रकार के दुष्प्रभाव पड़ सकते हैं, जैसे कि संज्ञात्मक, व्यावहारिक, मनोदशा और मिज़ाज संबंधित और निंद में गड़बड़ी, जिस का असर पारस्परिक संबंधों और सामाजिक गतिविधियों पर पड़ता है जिससे जीवन की गुणवत्ता बिगड़ती है।

दर्द को दो मुख्य श्रेणियों में वर्गीकृत किया जा सकता है--

(अ) नोसीसेप्टीव - जिसका संबंध ऊतक के नुकसान से है जो त्वचा, हड्डियाँ और आसपास के ऊतकों पर भी प्रभाव छोड़ता है।

(ब) न्यूरोपैथीक - यह नसों में उठने वाला दर्द है या फिर मिश्रित दर्द सिंड्रोम के रूप में उत्पन्न होता है जिसमें नोसिसेप्टिव और तंत्रिकाविकृति से उठनेवाले दोनों दर्द शामिल हैं। पार्किंसंस में खासकर दर्द का अनुभव नोसिसेप्टिव यानि व्यथित या व्यथित होने वाले ऊतकों के तंत्रिका के सक्रिय होने से होता है। इस के कारण है निरंतर कंपकंपी, मांसपेशियों में कठोरता, डीस्टोनिया, मांसल विकार (जैसे कि मोच, खराँच, गिरने के कारण हड्डियों का टूटना वगैरह) और सूजन। आपके नैदानिक लक्षणों को ध्यान में रखते हुए आप का विशेषज्ञ आपके दर्द के इलाज को निश्चित करेगा।

पश्चिमी आबादी में दर्द सूचित प्रसार के अनुसार पार्किंसंस विकार के मरिजों में ४६% से ८३% है परंतु यह आंकड़े शामिल किए जान के मापदंड के आधार पर जगह-जगह पर अलग हो सकते हैं। भारतीय अध्ययन के अनुसार यह प्रसार ५५% है जो करीब-करीब पार्किंसंस के दो मरिजों में से एक में होता है। दर्द अधिक वह बाजू में पाया गया जिस बाजू मोटर लक्षण ज्यादा थे।(७२%)

साहित्यिक कृतियों के अनुसार पार्किंसंस होने का कारण है सबस्तानसिया नाइया (जो मध्य मस्तिष्क के एक क्षेत्र में होता है) में डोपामाइन उत्पन्न करने वाली कोशिकाओं का खातमा। अगर सही और शीघ्र ही पार्किंसंस की चिकित्सा हो तो कड़ाई (कडापन) में सुधार हो सकता है और हलन-चलन की सीमा में वृद्धि हो सकती है जिससे दर्द की घटना कम हो।

पार्किंसंस से पीड़ित लोगों को दर्द क्यों होता है, उसकी पहचान कैसे करनी चाहिए और उसे कैसे निपटाया जाए।

सौभाग्य से दर्द के इलाज के लिए कई विकल्प मौजूद हैं। लेकिन आपके लिए कौनसा विकल्प सही है यह कैसे पता लगे? सबसे पहले अपने चिकित्सक से बात करे जो आपके दर्द का आकलन करे और उसके आधार पर खास आपके लिए एक दर्द प्रबंधन योजना बनाए।

सबसे नैदानिक उपकरण है नैदानिक इतिहास (क्लिनिकल हिस्ट्री) जो पार्किंसंस के दर्द के प्रकार की पहचान करने के लिए आवश्यक है। अपने चिकित्सक के साथ विस्तारपूर्वक दर्द के अनुभव की चर्चा करे।

अब देखते हैं विभिन्न प्रकार के दर्द का मूल्यवान और उनके प्रबंध की रणनीतियाँ।

१. पार्किंसंस में ज्यादातर दर्द का उभरना शरीर के अलग अलग हिस्सों में ऐंठन और छटपटा देने वाले लक्षणों के कारण होता है जैसेकि कठोरता, कॅपन, गति-अक्षमता (एकायनीस्या), आसनीय असामान्यताएं। पार्किंसंस में मांसपेशियों में ऐंठन और जकड़न शरीर के किसी भी हिस्से में हो सकती है, पर ज्यादातर गले में, भुजाओं में, पैरा - रीढ़ की हड्डी, पिंडली (काफ़) की मांसपेशियों में होता है। जबकी जोड़ों का दर्द ज्यादातर कंधे, घुटने, कमर और टखने में होता है। मांसपेशियों और हड्डीओं में होने वाला दर्द ४५% - ७४% पार्किंसंस से पीड़ितों में देखा गया है। इस मसक्यूलोस्केलेटल दर्द का इलाज उसके होने के कारणों पर निर्धारित है।

अगर इसकी मुख्य वजह है पार्किंसंस संबंधी कठोरता तो डोपामिनर्जिक औषध और फिजियोथैरेपी और व्यायाम इसमें मदद करते हैं।

२. एक और अन्य किसम का दर्द है रादिक्यूलर - न्यूरोपैथिक दर्द जिसमें नस या जड़ में दबाव की वजह से नस की जड़ के स्थान पर दर्द या सुन्नपण या दुर्बलता महसूस होता है। इसका प्रचलन है ५% - २०%। पार्किंसंस की वजह से हुए आसनीय असामान्यताएं और डिसतोनिया की वजह से रीढ़ की हड्डी में बदलाव, जोड़ों गठिया (आर्थराइटिस), स्लिप डिस्क हो सकता है जो नसों पर दबाव डालता है और जिसके कारण कटिस्नायुशूल (सायॉटिक) दर्द महसूस होता है। इसका प्रबंध बहु - विषयक होना चाहिए जिसमें शामिल है फिजियोथैरेपी, दवाईयाँ या एक्स - रे के मार्गदर्शन से रीढ़ की हड्डी के डिस्क में दिए इंजेक्शन।

३. डिसतोनिक ऐंठन के कारण गंभीर दर्द हो सकता है। यह कंपकंपी, या सहज, या किसी हालचाल या हाथ-पांव, चेहरे, गलकोष की मासपेशियों की गतिविधियों की वजह से हो सकता है। यह ८% से ४७% मरीजों में देखा गया है।

४. केंद्रीय दर्द एक आग्रहपूर्ण दर्द है जो तंत्रिका वितरण तक ही सीमित नहीं है। इसमें न्यूरोपैथिक (तंत्रिकाविकृत) संवेदी लक्षण भी दिखाई देते हैं जैसे कि पॉरेसठीस्या (झुनझुनी और चुभन) या तीव्र दर्द। आम तौर पे पीड़ित इसे एक विचित्र और अस्पष्टीकृत अनुभव के रूप में दर्शाते हैं जो ज्यादातर अधिक प्रभावित तरफ और ऑफ - पीरीयड (दशा) में महसूस होता है। केंद्रीय दर्द शरीर के विभिन्न भागों में होता है जिसमें मुँह, छाती, पेट, मलाशय, योनि, और वृषण। केंद्रीकृत दर्द पार्किंसंस के १०% - १२% मरीजों में देखा गया है। डोपामिनर्जिक दवाई की तरफ इसकी प्रतिक्रिया अच्छी है, पर कुछ प्रतिरोधक मामलों में सामान्य न्यूरोपैथिक (तंत्रिकाविकृत) दर्द की दवाईयाँ या ट्राइसाइक्लिक हताशारोधी (एंटी - डिप्रेसेंट) दवाई ज्यादा काम कर सकती हैं। कभी कभी सक्त् दर्द में ओप्योद श्रेणी की दवाई दी जाती है लेकिन इसका इसतमाल सावधानी के साथ और दर्द चिकित्सक के निर्देशानुसार होना चाहिए।

५. ऑकठीझिया एक बेचैनीपूर्ण उत्तेजना है जिसका वर्णन व्यक्तिपरक बेचैनी या लगातार गतीविधी करते रहने के कष्टदायक आवेग के रूप में किया जा सकता है। लीवोदोपा के उपचार से इस दर्द में सामान्य सुधार आता है।

६. रेस्तलेस लेग सिंड्रोम (बेचैन पैर सहलक्षण) पार्किंसंस से पीड़ित लोगों में दर्द का एक अन्य कारण है। इसका वर्णन यह है कि यह एक संवेदी मोटर अशांति है जो रात में प्रमूख

होता है और हालचाल से इसमें आराम महसूस होता है। इसमें अत्यधिक और अरुचिकर अनुभव होते हैं (झुनझुनी या पॉरसथीस्या और डिसेसथीस्या) खासकर निचले छेरो में। यह ८% से २०% पार्किंसंस से पीड़ित लोगों में देखा गया है जबकी सामान्य जनसंख्या में यह केवल १% लोगो में पाया जाता है।

संभावित रूप से पार्किंसंस में दर्द को प्रभावित करने वाले कारक:

१. लिंग - कई चिकित्सकों ने दर्शाया है कि गर्दन और पीठ का दर्द महिलाओं में ज्यादा मात्रा में देखा जाता है।

२. पार्किंसंस की अवधि और कठोरता - पार्किंसंस की लंबी अवधि और मोटर लक्षण में उलझन के कारण दर्द की व्यापकता ज्यादा देखी गई है।

३. वैज्ञानिकों का मानना है कि खिन्नता (डिप्रेशन) जो प्रायः ४०% पार्किंसंस से पीड़ित लोगों में देखी जाती है उनमें यह दर्द के अनुभव में एक महत्वपूर्ण भूमिका निभाता है। उसी तरह तनाव और मांसपेशी दबाव जो व्यग्रता (एंड्रिजायती) के कारण होता है ओससे भी दर्द बढ़ सकता है। वर्तमान सबूत से पता चलता है कि खिन्नता दर्द के अनुभव की धारणा को बदल सकता है और इसका इलाज भी हो सकता है।

४. जिन पीड़ितों में पूर्व मौजूदा दर्द होता है जिसका संबंध प्रणालीगत रोगों से हो जैसे कि मधुमेह (डायबीटीस), अस्थि - सुषिरता (ऑस्टियोपोरोसिस), गठिया रोग या आयु संबंधी स्थितीयों (जोड़ों या डिस्क के रोग) या आसन की समस्याएं उन्हें निदान (डायग्नोसिस) के बाद भी पूर्व मौजूदा दर्द का अनुभव जारी रहता है। यह संभावित पार्किंसंस के लक्षण जैसे कि अकड़पण, एकाग्रनीजीया (गति-अक्षमता), मांसपेशीयों की ऐंठन और आसन संबंधी अस्थिरता के कारण और खराब भी हो सकता है।

५. जो व्यक्ती अपने दर्द पर ज्यादा ध्यान देता है और जिसकी प्रतिक्रिया दर्द के प्रति तनावपूर्ण हो उसे दर्द का एहसास ज्यादा होगा, उस व्यक्ती की तुलना में जो इस दर्द पर ज्यादा ध्यान न देते हुए उसे अपने रोजाना जीवन में महत्व नहीं देता। जिन लोगों को असहाय महसूस होता है कि दर्द पर काबू नहीं पाया जा सकता या दर्द का कोई इलाज नहीं है या दर्द के प्रबंधन के लिए कोई चिकित्सक नहीं, ऐसे लोगों में दर्द ज्यादा महसूस होता है।

दर्द का प्रबंधन

पार्किंसंस के हर चरण पर दर्द एक एहम समस्या है और हर विशिष्ट समस्या रोग की अवधि पर निर्भर करता है। डिसटॉया और डिसकायनीस्या से संबंधी दर्द पार्किंसंस के बाद के चरणों में होता है। दर्द स्पष्ट रूप से पार्किंसंस से पीड़ित लोगों की जीवन की गुणवत्ता को प्रभावित करता है।

क्योंकि पार्किंसंस में दर्द और संवेदी लक्षण विसृत श्रेणीका दरसाते हैं इसलिए दर्द के प्रबंध में बहु - विषयक दृष्टिकोण की सिफारिश की गई है। फिर भी देखा गया है कि 40% पार्किंसंस संबंधित दर्द से जूझते पीड़ितों को इलाज नहीं मिलता। दर्द का उपचार विशिष्ट प्रकार के दर्द पर आधारित है और इसका निदान दर्द के प्रकार के पूर्ण मूल्यांकन के बाद ही पता चलता है। इस बात को ध्यान में रखना जरूरी है कि एक नाप सभी को नहीं उचित रहता।

पार्किंसंस संबंधी दर्द के प्रबंध में औषधीय और गैर - औषधीय विकल्प दोनों शामिल हैं। दोनों विकल्पों के संयोजन से और अंतर - विषयक प्रतिमान से सर्वोत्तम दर्द नियंत्रण मिलता है। दर्द के उपचार में कुछ सामान्य विकल्प जो शामिल हैं:

- दवाईयाँ (दर्दनाशक और सहायक दवाईयाँ)
- भौतिक चिकित्सा (फिजियोथैरेपी)
- मालिश
- बोट्यूलिन टोक्सिन इंजेक्शन
- पोषण प्रबंधन
- व्यायाम
- ऐक्युपंकचर या ऐक्युप्रेषर
- मनोचिकित्सा या कोगनितिव बीहेव्यर थेरपी (संज्ञानात्मक - व्यवहार चिकित्सा)
- योग और खींच के व्यायाम और ध्यान अभ्यास
- सामूहिक चिकित्सा
- न्यूनतम धावे के (इनवेसिव) दर्द बाधा (ब्लॉकर्स): इसका इस्तमाल उन पीड़ितों में किया जा सकता है जिनको सामान्य उपचारों से फायदा न हुआ हो। इनमें दवाई ठीक निशाने पर वितरित करने के लिए एक्स - रे का मार्गदर्श न लिया जाता है और स्थानीय (लोकल) अनएस्थेसिया देकर किया जाता है।

व्यक्तिगत मार्ग अपनाने से दर्द पर श्रेष्ठ नियंत्रण पाया जा सकता है। नियमित पुनर्मूल्यांकन से इलाज में जरूरत के हिसाब से बदलाव लाया जा सकता है।

निष्कर्ष

पार्किंसंस से पीड़ित लोगों में दर्द एक महत्वपूर्ण गैर - मोटर लक्षण है। व्यक्तिपरक होने के कारण कभी कभार इसका निदान पूरी तरह से नहीं होता और इलाज में कमी रह जाती है। दर्द को संबोधित करना जरूरी है वरना यह रोजाना गतिविधियों , मनोदशा, नींद और जीवन के संपूर्ण आनंद के साथ हस्तक्षेप कर सकता है। जीर्ण दर्द की वजह से जो विशिष्ट समस्याएँ उभरती हैं वे हैं नींद में गड़बड़ी, कुपोषण, सामाजिक संबंधों से विच्छेद , शारीरिक और कार्यात्मक घटाव , उदासी, चिंता, सोच प्रक्रियाओं में दुर्बलता। ऐसे दर्द की वजह से स्वास्थ्य सेवा की लागत में वृद्धि हो सकती है।

व्यावहारिक रूप से दर्द के एहसास की संकल्पना, दर्द के ५ प्रकार में से ९ संबंधि प्रकार में की जाए तो कुछ मदद हो सकती है: दर्द मांसपेशियों में या हड्डियों में, दर्द तंत्रिकाओं में या रीढ़ की हड्डी की जड़ों में, निरंतर ऐंठन या छटपटाहट, आकठीस्या संबंधी बेचैनी, और दर्द जो पार्किंसंस के वजह से दिमाग में हो रहे रासायनिक परिवर्तन के कारण।

पार्किंसंस के उचित और शीघ्र उपचार से कठोरता में सुधार आ सकता है और गतिविधियों की पहुंच में वृद्धि हो सकती है जिससे दर्द में कमी आ सकती है। दर्द पर नियंत्रण पाने के लिए उसका मूल्यांकन व्यक्तिगत होना चाहिए और इसका प्रबंध बहु - विषयी होना चाहिए।

REACHING THE UNREACHED

By Sharmila Donde



Our community projects have taken roots and are growing fast. Most of our projects started by doing what was necessary for the community as per our objective of reaching out to children and adults suffering from debilitating neurological illnesses and providing timely and adequate treatment to these deserving and needy patients and



"Start by doing what's necessary, then do what's possible, and suddenly... you are doing the impossible."

— St. Francis of Assisi

families. We are trying to do what is possible so that we do the impossible....

We now have a team of ten community workers who are the pillars of our projects. At our centres, the community workers help the physiotherapist during the physio sessions. They also take sessions independently under the guidance of the physiotherapists. A training program on paediatric and adult physiotherapy was organised for the community workers. This has given them more skills and confidence to identify and treat patients.

Our Asalfa centre focuses on providing physiotherapy to children with neurological illnesses. Shifting to a bigger place in Asalfa has enabled us to provide group therapy through multidisciplinary approach in addition to individual therapy.

In Dharavi, a medical camp was held in December where neurologists from Hinduja hospital and KEM hospital examined 75 patients. Medication was given to these patients. These patients go to Daya Sadan where they attend group therapy sessions. The frequency of



Daya Sadan has increased to three times a week now to provide treatment to children and adults. Home visits in Muslim nagar continue with our physiotherapists visiting the patients once a week along with the community workers.

The number of patients attending our centre in BDD chawl has been steadily increasing. The centre that started rehabilitation of adults is now providing individual physiotherapy to children with neurological diseases.

Our rural project in Vasind continues to address senior citizens with neurological diseases. The group which only had men attending the group has women attending the group regularly. Many patients have shown improvement in their condition and do not want to miss their sessions.

In our tribal project, we completed survey of Motivahiyal, one village in Kaparada near Valsad and then held a neurological camp for the patients. Neurologists from Mumbai examined 95 patients. The patients regularly receive medication from Neurology Foundation. A physiotherapist from Valsad visits Motivahiyal twice a week to provide therapy to 20 patients. The patients are feeling better and come regularly for therapy at the centre. The community workers are trained by the physiotherapists from Mumbai who follow up and also provide therapy every week.

All our projects are well established now. We hope to reach the unreached through our work in the community.



Our Very First Online Community!



Parkinson's Disease and Movement Disorder Society and PatientsEngage have joined hands to provide an online platform for people with Parkinson's and their caregivers, offering a great amount of important content and discussions. PatientsEngage is a patient/caregiver focused healthcare platform for supporting the management of chronic diseases.

Our online community will enable patients and caregivers to

- a) **Read latest information and research regarding Parkinson's**
- b) **Read tips on tackling Parkinson's**
- c) **Be part of discussions with experts and also connect with patients with Parkinson's and their caregivers.**
- d) **And very importantly, share their own experiences!**

At PDMDS, our core team comprises of psychologists, physiotherapists and health care professionals. If you are a patient or a caregiver, you can now have all your queries answered by the required specialists.

We hope you register and join our community on PatientsEngage and keep the discussions productive and lively! If you have any trouble registering, please contact our helpline numbers. This collaboration will be successful if all of you participate and contribute to the discussions. To log in please visit : **www.patientsengage.com, or www.parkinsonssocietyindia.com**

We as a team welcome you all.

BEING AWARE ... *By Nishaat Mukadam*

Confusion takes over the faces of most people when they hear "Parkinson's Disease". This lack of awareness is what causes many people to be insensitive towards a person with Parkinson's leading to embarrassment or stigma associated with this condition. At the PDMDS we aim to remove any stigma associated with Parkinson's and to enable people with Parkinson's to function like any other person in the society and the best way to do this is to create awareness among the general public.

Over the last couple of months, the PDMDS team members have visited senior citizens at the Holy Family Church (Andheri East), St. Pius Church (Mulund West), the Holy Name Cathedral (Colaba), the Sobati Senior Citizens Group (Vile Parle East), the Visawa Senior Citizens Group (Andheri East), WIA senior citizens group at the Malabar Hill Club, the Rotract Club of Malabar Hill and the Indian Association of Secretaries and Professionals, and given talks on Healthy Aging, Parkinson's and other neurological disorders. We got a great response from all these centres with enthusiastic people volunteering to help us spread awareness about the condition.



The Adhata Trust, an organization for the welfare of senior citizens, invited the PDMDS members to perform at their World Seniors Day programme. One of our team member's, mimed the daily difficulties faced by a person with Parkinson's and the members of our Dadar support centre showed how exercise and other therapy has helped them overcome these difficulties by dancing to the song "Power". Their enthralling performance was met with a standing ovation from the audience.

We have also participated in Diwali exhibitions where we displayed diya platters, diya sets and greeting cards made by people with Parkinson's who attend our support centres in Mumbai. We had stalls at the Pink Potli Exhibition at Khar, the Centrum NGO Fair at Kalina, Tata Consultancy Services (TCS) at Goregaon and Vikhroli, Korum Mall at Thane, the Tata Institute of Social Sciences (TISS) at Deonar, and Kalimpong Art Gallery at Breach Candy. These exhibitions were not only a success, but also served as a platform for us to reach out to a larger audience and spread awareness about Parkinson's and the work of the PDMDS.

Ahmedabad: The Commencement of a new PDMDS chapter

By Rhea Wadhvani

"One of the most important things you can do on this earth is to let people know they are not alone."
— Shannon L. Alder

We're happy to announce the launch of our most recent PDMDS Chapter in Ahmedabad, Gujarat. We now have 6 centres functioning all over Gujarat, the others being Baroda, Bhavnagar, Mahuva, Rajkot and Surat.

We received an exceptional response on the inaugural day with registrations of 90 PWPs and 35 caregivers. Key note speakers at the inaugural event were eminent Neurologist Dr. Sudhir Shah who spoke on the Diagnosis of Parkinson's Disease, Dr. R S Bhatia (Neurologist, Ahmedabad) shared insights on Non-Motor Symptoms in PD, Dr. Charulata Sankhla, Neurologist & Movement Disorder Specialist, Mumbai, provided information on the Medical & Surgical Management in PD and Dr. Maria Barretto (CEO PDMDS), outlined the activities of PDMDS and the importance of a Support Group.



The Ahmedabad centre is developing with a sizeable number of patients regularly attending the support group sessions. The feedback on our multidisciplinary modules for PD has been overwhelming. Our aim is to extend our reach in as many areas as possible through these Chapters, so that PWP's and their caregivers can benefit from the services we offer. The centre counts on your participation and active involvement in making this Chapter a great success. We need your valuable support in creating awareness and improving the quality of life of those suffering from Parkinson's disease.

Support Group Details:

Gujarati Sahitya Parishad,

Behind Times of India, Riverside, Ashram Road, Ahmedabad 380009.

Every Sunday between 10 a.m. -12 noon.

What is a PDMDS chapter?

Chapters and Support Groups are formed to provide local assistance for those suffering from Parkinson in the area. They are community organizations that provide people with Parkinson's and their caregivers access to local resources and services, such as Support Groups, Rehabilitation, Multi-Disciplinary Model of care, Education Programs, Medication & Assistive Aids & much more. Chapters educate the community about Parkinson's disease and raise awareness to help ensure that people with Parkinson's, their families and caregivers lead a normal life.

Extend the Xcel advantage
in both early & late stages of PD

ROPARK XL
Ropinirole Hydrochloride 1.2/4 mg

Simplifies movements... Simplifies life all day long



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SUN PHARMA

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stages of PD

RASALECT
Rasagiline 0.5mg / 1mg

Precise Action...Multiple Benefits



SYMENTA
A Division of
SUN PHARMA

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SYNDOPA CR125
Levodopa 100 mg + Carbidopa 25 mg controlled release tablets

Gives them the enjoyment of normal life



SYNERGY
A Division of
SUN PHARMA

SUN
PHARMA



Have a Doubt? **ASK THE DOCTOR**

"I have been diagnosed with Parkinson's but I don't have tremors. I experience balance problem, swallowing difficulty, drooling, and frequent falls..Is it possible to have Parkinson's without tremors?"

All people with Parkinson's do not have tremor. Parkinson's has a large number of symptoms but every PwP will not experience all the symptoms as Parkinson's tends to affect each person in a different way. For example, some people may predominantly have tremor as their major symptom, whereas others like seen in your case may have problems with balance and walking, swallowing, etc.

"One of my friends is affected by PD at age 43 & his son was 14 yrs age. What are the chances of genetic transmission of PD to his son or is there more chances of PD to son than a normal person whose father not affected by PD. No other person in family in last 3 generation was having PD"

Most cases of Parkinson's disease are not genetic in nature. Only 5% of cases have a genetic basis. Even in these 5% the penetrance of the gene is less than 30% indicating that even if the son got the gene (which itself is less than a 5% chance), the chance of him getting PD is less than 1/3rd. For all practical purposes this risk is minuscule hence the family should not be concerned.

"Is NEUPRO patch treatment effective to treat Parkinson's disease?"

The NEUPRO Patch delivers the dopamine agonist rotigotine through the skin, directly into the bloodstream. It releases the medicine 24 hours a day, providing stable, continuous delivery of medication. It is believed that dopamine agonists work by stimulating dopamine receptors in the brain; however, the exact way NEUPRO treats PD is unknown. Do not use NEUPRO if you are allergic to rotigotine or any of the other ingredients in the patch.

"My father is 63 yrs old and he is diagnosed with early stage of PD from past 2 yrs and currently he is taking syndopa plus tablet 4 times a day, whenever he takes this tablet he feels tired and sleepy, what is the remedy for this problem and if he does not take this tablet he will not either feel tired nor sleepy"

There are many reasons for a patient to become sleepy and lethargic. Some of the common ones include an infection, constipation, sudden drop in the blood pressure (orthostatic hypotension) after taking the drugs (which can be detected by measuring the blood pressure and heart rate after lying down for 3 min and then standing after 3 min) or then the drugs themselves like dopamine agonists. Obviously the strategy changes depending on the cause. You need to ask your neurologist to evaluate the possible causes. Syndopa (Levodopa and Carbidopa) has side effects but it also is a lifeline to patients with Parkinson's disease so please do not blame every possible problem on it.

"I have Parkinson's since 8 years, I experience major problem of severe constipation than any other. Is constipation drug induced or disease induced?"

Constipation is a troublesome complaint experienced by many Pd patients. It is due to the Pd itself and also to a great extent, aggravated by the use of anti PD drugs. Almost all PD drugs can worsen constipation, but the worst offender is anticholinergic medication (pavitane). As far as possible, it would be better to reduce or stop this medication, especially in elderly patients. Taking plenty of water, fruits (papaya and figs) and vegetables would also help in constipation. Stool softeners (softovac), laxatives (dulcolax) and in some cases enema may also be needed.

MULTIDISCIPLINARY INTERVENTION PROGRAM

CENTRAL & EASTERN MUMBAI (SUBURBS) SUPPORT CENTRES

Chembur (E):

Seva Daan Special School
St. Anthony's Rd, Near OLPS Church
Chembur (E), Mumbai – 400 071

Support Group Meeting:

Third Saturday of every month: 10:00 a.m. – 11:00 a.m.

Physiotherapy:

1st & 3rd Monday of every month: 10:00 a.m. – 11:00 a.m.

Ghatkopar (E):

Smt. Pramilaaben Dand Rotary Service Centre
R. N. Gandhi English School Lane
Rajawadi, Ghatkopar East

Physiotherapy:

2nd & 4th Monday of every month: 10:30 a.m. – 11:30 a.m.

Mulund (W):

St. Pius X Community Centre
Seminar Rm. No. 2, Ground Floor
St. Pius X Church, Nahur Road
Mulund (W), Mumbai – 400 080

Physiotherapy and Support Group Meeting:

Every Wednesday of the month: 10:30 a.m. – 11:30 a.m.

Thane (W):

St. John the Baptist Church, Senior Citizen Hall,
Gr. Floor, Jambhli Naka, Opp. Masunda Tank, Thane (W)

Physiotherapy and Support Group Meeting:

Every Friday of the month: 10:30 a.m. – 11:30 a.m.

NAVI MUMBAI SUPPORT CENTRE

Vashi:

Specialty Physiotherapy Department
MGM Hospital, Sector – 3
Vashi, Navi Mumbai – 400 705

Support Group meeting:

Fourth Wednesday of every month: 12:00 p.m. – 1:00 p.m.

Physiotherapy:

Every Wednesday of the month: 10:30 a.m. – 11:30 a.m.

COMMUNITY BASED REHABILITATION FOR NEUROLOGICAL CONDITIONS

BDD Chawls :

Sanghi Medical Centre, Opp. Chawl No.113, Worli

Every Friday 10:00 a.m. - 12:00 p.m.

Dharavi :

Daya Sadan, S. M. Chawl, Nr. Old Police Station, Dharavi

Every Thursday 2:00 p.m. to 4:00 p.m.

SPECIALITY SPEECH THERAPY, MUMBAI

Ali Yavar Jung National Institute for the Hearing Handicapped

Bandra Reclamation, Bandra (W)
Tel.: 022-26404977 Extn. 329/ 310

OUTREACH CENTRES

Nashik :

Tel: Ms. Verna Quadras - 9225127770

Sharadagram, Indiranagar : First Saturday of the month

Don Bosco School College : Second Saturday of the month

Bishops House Jail Road : Third Saturday of the month

Maria Vihar, Gangapur : Fourth Saturday of the month

11:00 a.m. – 12:30 p.m.

Goa :

Ms. Joanne D'souza - 0832-2268304; 9923288429
pdmds.sg.goa@gmail.com

Panjim: YMCA International,

Behind Parade Ground, Next to Home Science College, Campal.

Mapusa: Emmaus Counselling Centre,

Run by Carmelite Fathers, Reis Da Costa House, Feira Alta.

Margao: B.P.S. Sports Club

Hyderabad :

Tel: Meghana Srinivasan - 07036212963

Nizam Institute of Medical Sciences, Punjagutta.

Please Contact PDMDS for venue and date of monthly meetings.

Every Second and Fourth Saturday of the month
4:00 p.m. - 6:00 p.m.

MULTIDISCIPLINARY INTERVENTION PROGRAM

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Nizam Institute of Medical Sciences, Punjagutta.
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Every Second and Fourth Saturday of the month
4:00 p.m. - 6:00 p.m.

MULTIDISCIPLINARY INTERVENTION PROGRAM

OUTREACH CENTRES – IN COLLABORATION WITH BKP – PDMDS

PUNE

Tel: Dr. Vrushali Belekar - 09960981692

Deenanath Mangeshkar Hospital,
Erandawane, Near Mhatre Bridge, Pune 411004.

Every first, third and fourth Saturday of the month,
10:00 a.m. – 12:00 p.m.

BHAVNAGAR

Tel: Mr. K. D. Padia - 09374865307

PNR Society,
51, Vidyannagar, Bhavnagar 364002

Every Sunday of the month:
11:00 a.m. – 1:00 p.m.

MAHUVA

Tel: Dr. Bhavin Mandaviya - 09726950909

C/o K B Parekh College,
Jadara Road, Mahuva 364290

Every Second and Fourth Saturday of the month at
4:00 p.m.

BARODA

Tel: Dr. Manali Shah – 8306866988/ 9328366988

Balvant Parekh Centre for General Semantics,
C-402, Siddhi Vinayak Complex,
Behind Vadodra Railway Stn, Faramji Rd.

Every Saturday of the month,
4:00 p.m. to 6:00 p.m.

SURAT

Tel: Dr. Hetashri Patel – 9033577631

C/o Shreenath Niranjana Badrikashram Trust,
Badrinarayan Temple, besides BAPS Swaminarayan Hospital,
Adajan.

Every Sunday of the month,
11:00 a.m. to 1:00 p.m.

RAJKOT

Tel: Dr. Priti Chavda – 09909909547

Sir Lakhajiraj Library,
Nr. Bapuna Bawla, Trickon Bag Chowk.

Every Sunday of the month,
10:30 a.m. to 12:00 p.m.

AHMEDABAD

Tel: Dr. Dhvani Parikh – 9537160633

Govardhan Shmruti Mandir,
Gujarati Sahitya Parishad, Behind Times of India,
Riverside, Ashram Road, Ahmedabad 380009

Every Sunday of the month,
10:00 a.m. to 12:00 p.m.

OUTREACH CENTRE IN COLLABORATION WITH PARKINSON'S DISEASE SOCIETY KARNATAKA

BANGALORE

Tel: Rohini Bharath - 09986035938

Please Contact PDMDS for venue and date of monthly meetings.

IN COLLABORATION WITH PARKINSON'S DISEASE PATIENTS WELFARE SOCIETY KOLKATA

Tel: Ms Majumder - 91 9830821124

Email: pdwskolkata@gmail.com



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www.instagram.com/parkinsonsocietyindia

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Room 131, Bombay Hospital, 12 Marine Lines, Mumbai 400 020

Office Address: Gala 260,
A to Z Industrial Estate, Lower Parel (W), Mumbai 400 013
Tel: 022 2497 7477, +91 9987216057



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