



## **SUPPORT AND REHABILITATION OF PEOPLE WITH PARKINSON'S AND THEIR CAREGIVERS AND TO PROMOTE HEALTHY AGEING THROUGH EDUCATION AND AWARENESS ABOUT NEUROLOGICAL CONDITIONS**

### **Project Impact Update: 20<sup>th</sup> November to 21<sup>st</sup> December 2021**

The Parkinson's Disease & Movement Disorder Society (PDMDS) through its network of support centers provides free of charge ongoing education and therapy through a community based 'Multidisciplinary Model of Care' for People with Parkinson's (PWP's) and their families all over India. Through the CSR funds allocated by EKC Ltd for the project 'Support and rehabilitation of people with Parkinson's and their caregivers and to promote healthy ageing through education and awareness about neurological conditions,' PDMDS is sustaining its current community – based multidisciplinary services at its Thane, Mulund and Dombivali centers near Mumbai. Due to the present unforeseen situation of Covid- 19 pandemic and as per the government directive, all the programs for PwP's and their caregivers are successfully being run online.

A total of 408 beneficiaries (163 PwPs and 245 Caregivers) are a part of this project and getting two or more services of online group multidisciplinary rehabilitative therapy, need based individual counseling services, education and awareness initiatives, distribution of resource material, patient welfare.

Among the total PwPs enrolled in the project, 3 new PwPs joined the Thane support center in the current update period. Total 8 weekly online sessions each in Mulund, Thane and Dombivali (total 24 sessions at three centers). One young onset Parkinson's patient from Thane attends the special YOPD group sessions on Saturdays. Around 54 PwPs attend the weekly online group therapy sessions. 3 PwPs get weekly speech exercise sessions. All PwPs get phone calls from the staff or volunteers for regular follow up as they don't want to join online sessions or don't have smart phones or don't understand technology or there's no one to help them join online. One PwP and his caregiver were counselled individually by PDMDS psychologists. One special monthly session was taken separately for caregivers.

## ACTIVITIES DURING THIS PERIOD:

### **1. Technology assisted support and rehabilitation:**

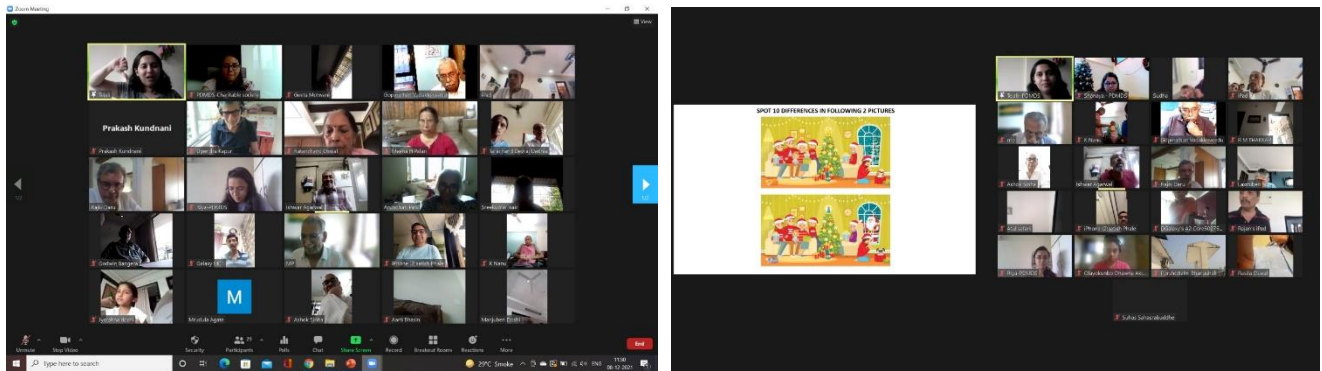
Multidisciplinary group – based rehabilitation for PwP's using digital platforms is being conducted on a weekly basis. **Technology assisted rehabilitative therapy** consisted of Physiotherapy and psycho education sessions. Session topics that are created and conducted by the physiotherapists and psychologists included:

- Tai Chi
- Tai Chi with Louhan patting and breathing exercises
- Trunk Exercises
- Balance Exercises
- Anxiety in PD
- Diet and Nutrition Part 1 and Part 2
- Christmas session

Additionally, participants were also shown short clips from the previously held webinars and PDMDS videos that were relevant to the respective topics.

A special session of Antakshri was held along with Tai Chi and breathing as relaxation activity. As part of the Diet and nutrition session we had asked PwPs to make simple food dishes which have dopamine enhancing foods and send the picture. One of the photo sent by the PwP is given below. Celebrating Christmas, a special session is being held this week in all groups wherein cognitive activities of attention and memory are based on Christmas theme and creative activities of dance and music based on Christmas carol and making a Christmas shaker is being conducted. The picture of the activity is shown below





### Feedback from the members:

1. Mr Prakash Jain, Dombivali: Taichi session was great. It is done slowly so I felt relaxed while exercising. We should have more sessions like this.
2. Mr Rajendra Chaware, Thane: All of us are always experiencing a lot of anxiety. How to recognize anxiety and fear and the grounding activity was nice. I have started practicing it to distract myself.

**Caregiver sessions** are being held once a month. This month's CG session was a yearend question and answer session wherein many doubts regarding PD was answered by the therapists. Questions regarding nightmares, how to get up from toilet seat, and hallucinations were asked. They also wanted to know the following:

- how the sleep pattern could be changed as PwP sleeps during the day and wakes up middle of night
- how to deal with PwP who is stubborn especially when doing things which can be dangerous e. g using knife, walking in bathroom without assistance etc
- tips on Memory
- if psychological symptoms are a part of PD as PwP shows more depressive symptoms since diagnosed

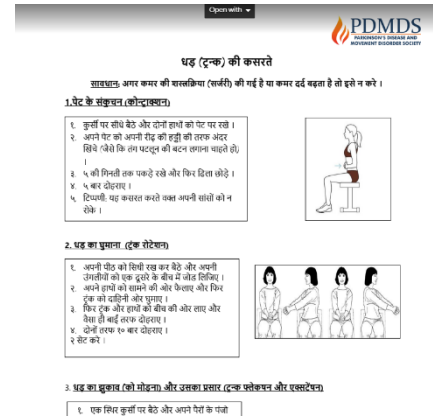
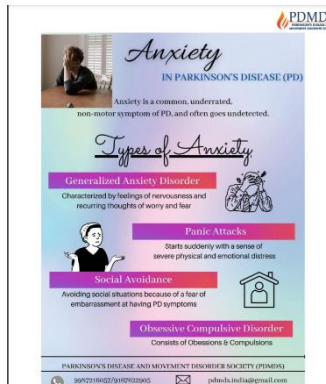
Information was provided for these queries and PDMDS created resources were shared. Approximately 10 CGs also attend the regular sessions along with their PwP member so that whatever is taught in the session is practiced at home.

## **2. Patients Welfare**

3 PwPs from Thane are being given medicines for Parkinson's Disease as part of patients' welfare services.

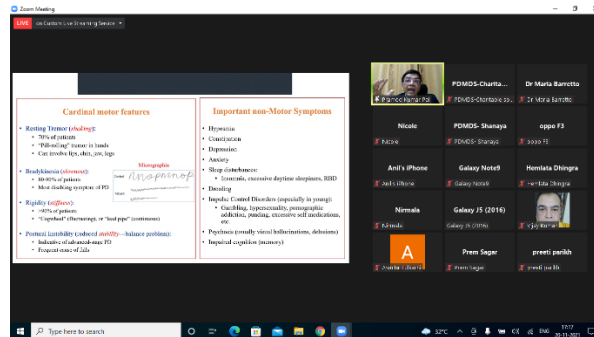
### 3. Distribution of resource material and information dissemination

PDMDS designed and developed educational and video resources for People with Parkinson's (PWP's) and caregivers in the update period so that PwPs could have the information to follow at home and those who have missed out can also get the information. 8 handouts of home exercise program with information in Hindi and English, 8 weekly sessions for online group meetings for therapists and 5 videos for PwPs were distributed.



### 4. Awareness and Education Prorammes

A webinar was held on 'Medical and Surgical management of Parkinson's Disease' by Dr Pramod Pal, professor of neurology, NIMHANS, Bangalore for the patients of PDMDS and their caregivers. Members from all the three project centres attended the webinar.



5. **Healthy ageing program-** PDMDS identified one old age home in UlhasNagar with 53 residents. Three visits to the home have been done to identify their needs. One group session of warm up exercises with 9 residents has been conducted. 7 residents have been individually counselled or given exercise tips for pain and other physical conditions.

