



International Parkinson and
Movement Disorder Society

**MDS Health Professionals Special Interest Group
(MDS-HP-SIG)**

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MDS-HP-SIG Basecamp Meeting (ONLINE)

Young Onset Parkinson's disease
March 3-6, 2017

Meeting Intent: A focused discussion surrounding Young Onset Parkinson's disease (YOPD).

Introduction to Young onset Parkinson's

Parkinson's occurring in younger people has many challenges over the duration of illness, such as the need to continue working and managing family life and in some cases raising children. For many people living with young onset Parkinson's, there is a need to access a range of health care professionals, often for many years to get the best symptoms management.

Purpose and Aim of focused Meeting on Basecamp

To date, there is little research into how the needs and models of care may differ for people with young onset Parkinson's. In this base camp meeting we have the aim of discussing this issue and share our experience of delivering care and how we meet the needs of people with Young Onset Parkinson's.

AGENDA

To help focus the discussion, please provide your comments to the following, regarding YOPD:

I. SERVICES AND SUPPORT

- Are people able to access Multidisciplinary care in your location/region?
- Do you have a medical / health professional team with a particular interest in Young Onset Parkinson's (YOPD)?
- Is there capacity to deliver a MD Service responsive to the needs of people with YOPD? i.e. *After hour's clinics/ increased use of virtual or online therapy*
- What additional support do people with YOPD need? And are they available? i.e. *specific peer Support Groups*

II. CHALLENGES AND SOLUTIONS

- Please provide examples of challenges you have observed, experienced by people living with YOPD.
- What challenges have you, as a health care professional, experienced in planning and delivering care for people living with YOPD?
- As a health care professional what other challenges have you identified in managing people with YOPD?
- What strategies have you used or are you aware of to meet these challenges and promote better care?
- Pregnancy and Parkinson's – there is little published information on managing Parkinson's and pregnancy. Does anyone have any experience they are able to share?

III. ADVANCED THERAPIES AND TECHNOLOGY

- Do a greater percentage of people with YOPD get referred /or receive DBS than the typical onset of Parkinson's?

IV. OTHER INFORMATION

- Is there any other information you would like to share which may enhance the care provided for people living with Young onset Parkinson's and their families?