



PD_Pal - Palliative care in Parkinson's disease

Parkinson's Disease (PD) is the second most common neurodegenerative disorder and is characterized in its advanced stages by motor and non-motor complications causing progressive loss of autonomy in activities of daily living, poor quality of life, marked caregiver distress, and high utilization of medical services. Similar to cancer patients, albeit for much longer duration, PD patients have considerable (and mounting) unmet physical, psychosocial and spiritual needs, and experience great problems with continuity of care.

The overall ambition of PD_Pal is to validate a new model of palliative care which would be easily integrated with traditional management when disability limits mobility and independence. PD_Pal will provide an added layer of support to patients, their loved ones, and treating clinicians.

PD_Pal randomised controlled trial will provide evidence on the effectiveness of specialized, multidisciplinary, outpatient palliative care intervention (Advance Care Planning) in improving family satisfaction, symptom management and quality of life. PD_Pal will also further prove the feasibility and economic sustainability of this approach by the active involvement of patients lay associations as well relevant medical societies.

PD_Pal team includes leading experts in both neurology and palliative care with key-roles in both national and international PD working groups. PD_Pal will develop a new set of evidence-based Guidelines and a Massive Online Course (MOOC) for Palliative Care in PD involving in the process experts from the European Association for Palliative Care, the European Academy of Neurology and the Movement Disorders Society. Thus, PD_Pal is best positioned to transfer this knowledge to all European countries and ensure that "PD_Pal Guidelines" will translate into best practice. The PD_Pal MOOC "Best Care for People with Late Stage Parkinson" will be integrated into the WHO supported interdisciplinary post-graduate palliative care curriculum.

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