SELF MANAGEMENT & CO-PRODUCTION WEBINAR
“New realities, new challenges in Parkinson’s care”

21/09/2022
Aim

Improving the quality of life of people affected by Parkinson’s disease and their families for more than 25 years

Figures and features

- We are more than 1,900 members (patients, family members and carer providers)
- We are formed by 58 professionals and coordinate over 151 volunteers
- We conduct research at clinical, technological and social levels
- We perform more than 36,000 therapies and 1,770 social interventions annually
- Advocacy in collaboration with policy makers
Strengths

Direct assistance to patients and carers
- Rehabilitation and telerehabilitation
- Psychology and cognitive stimulation
- Social intervention: including leisure and free time, volunteering...

Dissemination and training
- Awareness campaigns
- Conferences
- Training courses (patients, relatives, professionals...)
- Workshops

Research and innovation
- Involved in European projects since 2001
- Currently engaged in 4 European projects (Horizon 2020, IM2, ERAPlanMed)

Advocacy
- Public policies that improve and increase resources
- Ensure the rights of patients (and carers)

Areas of expertise

- Public policy impact
- Patient engagement
- Cocreating (Real needs)
- Dissemination, Communication and Scientific publications
- Validate and evaluate prototypes and processes
- Piloting experiences, processes, prototypes (Sample: 3,800 persons)
Research
Committed to Research since 2001

Personalised Database
Innovation in therapy techniques, tools
(CognPark, Droolpark, dysphagia unit)
National and European Network
(EPDA, CERMI, European Brain Council, SEN, FEVOCAM, FEMADEN, and FEP)
Engaged in several European projects
(Horizon 2020, IMI2, ERA Per Med)
External Patients Advisor (Paradigm project)

Communication

14 annual impacts on media
36 newsletters were sent to 7,556 people
4 annual magazines, with a circulation of 2,200 copies

Our website www.parkinsonmadrid.org
360,070 sessions open so far this year
199,823 annual users
7,556 people subscribed to our newsletter

More than 21,556 followers today

Facebook 6,929 followers
www.facebook.com/parkinsonmadrid

YouTube 6,643 followers
www.youtube.com/parkinsonmadrid

Twitter 5,854 followers
www.twitter.com/ParkinsonMadrid

LinkedIn 2,131 followers
www.linkedin.com/company/asociacion-parkinson-madrid
APM - CARE PATHWAY

Requested Information (phone; face-to-face; networks)
https://www.parkinsonmadrid.org/

First patient interview | Department of Social and Health Care
(Administrative and clinical management - Parkinson Net)
First Assessment with social and/or clinical referral

Second patient interview | Social referral - Department of Social and Health Care
First complete social evaluation
Second patient interview | Clinical referral - Department of Therapeutic Care
First complete therapeutic evaluation

Design a personalized plan according to the user needs
Different programmes and activities
Departments of Social and Health Care & Therapeutic Care

Regular follow-up appointments and regular social/clinical assessments
Every 6 months / 1 year
Departments of Social and Health Care & Therapeutic Care
NEW CHALLENGES | SOCIO-DEMOGRAPHIC

Major changes

• Ageing (13.8 million in 2018 -> 31.8 in 2050), chronic diseases and dependency (life expectancy increases, not healthy life years; in number and proportion; 93% elderly have problems in at least one instrumental activity).

• Comorbidity and multimorbidity (72.5%).

• More older population living in cities, alone, with fewer children (only children, older, fewer informal carers).

• Unsustainable public spending on health and care (Spain: 28 million full-time unpaid care jobs/ to meet all the demand for care; 30% of the labour market).

![Graph 1](image1.png)

**Figure 14 - Self-reported longstanding illness or health problems, by age class, 2017**

![Graph 2](image2.png)

**Figure 17 - Self-reported chronic diseases, by sex and age class, 2014**
NEW CHALLENGES | SOCIO-DEMOGRAPHIC

**Parkinsons**
- Estimated annual cost of 13.9 billion euros; 11,600 euros/patient.
- Public expenditure on health and care unsustainable.

**Health and care**
- Shaping new models of care.
- Multidisciplinary care teams with new or redesigned roles for care professionals.
- Active cooperation between health professionals and patients (at European level).
- Integration of promotion and prevention in primary care. Individuals take responsibility for their own care.
- Use of digital solutions (wearable devices, mHealth apps) -> efficient, cost-effective, sustainable, customisable care (research, diagnosis, treatment).
CO-DESIGNING DIGITAL CARE
NATIONAL PROJECTS

• “Tele-rehabilitation”

• “New realities new challenges”

• “E-inclusion Parkinson”
EUROPEAN PROJECTS

Promoting quality of life for older people: Digital user-centred care system

- **AffecTive basEd iNtegrateD carE for better Quality of Life (TeNDER)** [https://www.tender-health.eu/](https://www.tender-health.eu/)

- **Identifying Digital Endpoints to Assess FAtigue, Sleep and acTivities in daily living in Neurodegenerative disorders and Immune-mediated inflammatory diseases (IDEA-Fast)** [https://idea-fast.eu/](https://idea-fast.eu/)

- **PeRsOnalized Integrated CARE Solution for Elderly facing several short or long term conditions and enabling a better quality of LIFE (PROCare4Life)** [https://procare4life.eu/](https://procare4life.eu/)

EUROPEAN PROJECTS

Promoting quality of life for older people: Digital user-centred care system

- **ECare4PD | Programa Erasmus+**

- **SUPER | Programa Erasmus+**
Thank you!

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