

Recommendations for the organization of multidisciplinary clinical care teams in Parkinson's disease

DEVELOPED BY EXPERT CENTERS AND PATIENT ORGANIZATIONS

A. ELEMENTS FOR OPTIMAL CARE

RECOMMENDATIONS

- There is mutual trust between team members and respect for diversity of professional roles and perspectives.
- Team members believe in the benefits of multidisciplinary care and are motivated to provide it as a joint effort.
- Parkinson's disease (PD) care is broader than just for PD alone. All team members promote general health and well-being, as well as the prevention of other diseases.
- There is a core care team* available for newly diagnosed PD patients. Team members are available depending on patient needs and specific situations.
** Members of the team are described in section B*
- Follow-up consultations by neurologists are scheduled depending on patient needs and disease complexity, but at least once a year. For allied healthcare, the frequency depends on individual needs.
- Patients do not have to be seen by a neurologist at every follow-up visit. Depending on their needs, they may be seen by a PD nurse specialist or another member of the core team.
- Clinical care teams are transparent about which elements of good multidisciplinary care they offer. Consequently, patients know what to expect and the team knows what elements are missing and where there is room for improvement.

- Healthcare providers working in nursing homes or on general hospital wards receive dedicated training in managing PD.*
- Continuity of care is essential. This is defined as the first point of contact with the healthcare team, which is then harmonized by continuous communication with the other required healthcare providers.*

** These recommendations were emphasized by the patient organizations*

CONSIDERATIONS

- Care is non-hierarchical and all team members have a respected voice. The final treatment decision and liability depend on the specific problem(s) and the expertise of the disciplines involved.
- All team members perform their job within their formally-defined scope of practice. They are aware of each other's strengths to facilitate optimal collaboration and referral.

ABBREVIATIONS

PD = Parkinson's disease
 Caregiver = the informal caregiver(s) of the person with PD
 Care partner = the informal caregiver of the person with PD

RECOMMENDATION

An essential element ('must have') in the organization of multidisciplinary care for people with Parkinson's disease (PD)

CONSIDERATION

A desirable element ('nice to have') in the organization of multidisciplinary care for people with Parkinson's disease (PD)



B. MEMBERS OF THE TEAM

B1. CORE TEAM OF EACH PATIENT

RECOMMENDATIONS

- The following healthcare professionals are part of the core care team:
 - Dietician
 - Movement disorder neurologist
 - Occupational therapist
 - Parkinson's disease nurse specialist*
 - Physiotherapist
 - Psychiatrist or (neuro)psychologist
 - Social worker
 - Speech and language therapist

** This may also be a nurse practitioner or registered nurse*
- Effective and efficient lines of communication between team members are essential to signal possible crises regarding patient care or context and divert them in due time.
- All team members are flexible and have the capability to learn from each other, especially from persons with PD and their care partners.*

** These recommendations were emphasized by the patient organizations*

B3. THE IMPORTANCE OF VARIOUS TEAM MEMBERS

RECOMMENDATIONS

- All core team members are potentially important in all disease stages, but the contribution of each team member depends on patient needs.

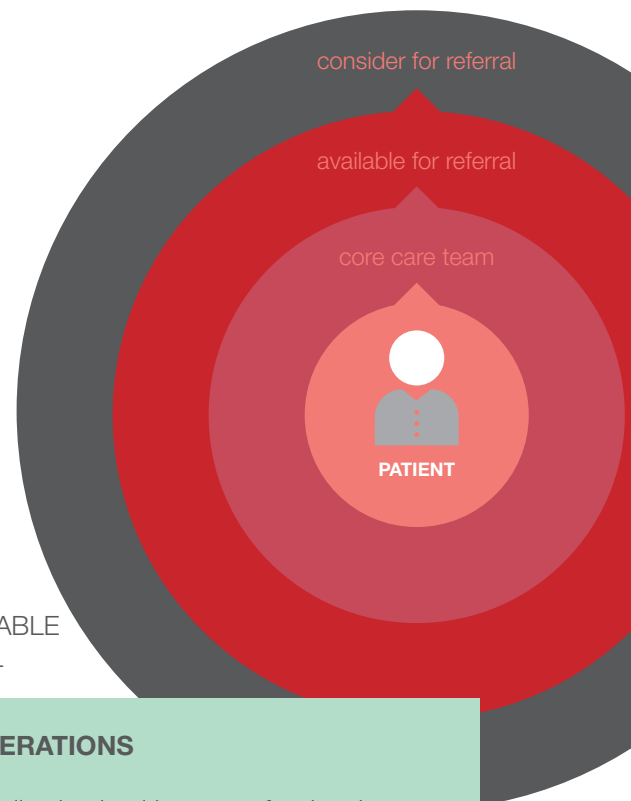
B2. HEALTH DISCIPLINES AVAILABLE FOR FREQUENT REFERRAL

RECOMMENDATIONS

- The following healthcare professionals are available for referral:
 - Gastroenterologist
 - Geriatrician
 - Neurosurgeon
 - Nursing home physician
 - Pain specialist (usually an anesthesiologist)
 - Urologist
- The primary care physician has an essential role in the community, in making referrals to medical specialists and in the palliative stage of the disease.

CONSIDERATIONS

- The following healthcare professionals can be considered for referral:
 - Clinical geneticist
 - Dentist
 - Internist
 - Neuro-ophthalmologist
 - Pulmonologist
 - Rehabilitation specialist
 - Sleep consultant



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C. ROLE OF PATIENT AND CAREPARTNER

RECOMMENDATIONS

- The care partner is involved from the moment of diagnosis.
- Patients and care partners are engaged in shared decision making to determine treatment approaches, i.e. by jointly prioritizing issues and problems for the treatment plan.
- Care is organized in a patient-centred way, adopting patients' and care partners' goals of care, health and well-being.
- Patients and care partners are aware of and have access to relevant and reliable educational resources to enable self-management, for example specific patient-related material.
- Caregiver strain is evaluated and treated.
- Patients and care partners evaluate the quality of perceived care.
- Time constraint of professionals is an important limitation to allow for optimal patient participation. To improve this, sufficient consultation time is needed.

- Patients and care partners are involved in their care, for example by inviting them to*: be involved in decision making about their treatment plan; (sometimes) participate in team meetings; participate in advisory boards for monitoring and developing care delivery; and/or complete questionnaires about care satisfaction and provide feedback regarding healthcare.

CONSIDERATIONS

- Patients and care partners are involved in their care, for example by inviting them to*:
 - be involved in decision making about their treatment plan
 - (sometimes) participate in team meetings
 - participate in advisory boards for monitoring and developing care delivery
 - complete questionnaires about care satisfaction and provide feedback regarding healthcare

** Examples to involve patients and care partners; this list is not exhaustive*

D. COORDINATION OF THE TEAM

RECOMMENDATIONS

- The patient's care team has a team coordinator. The patient and team members are aware of who this is.
- Care coordination is of critical importance in all disease stages. However, what it looks like varies per stage and depends on patient needs.

CONSIDERATIONS

- The team coordinator is either the (specialized PD) nurse, or the most suitable person in the team regardless of their discipline (i.e. someone with leadership, communication and organizational skills).
 - * The movement disorders center determines the team coordinator assignments*
- Treatment related decisions are integrated into a shared treatment plan by the team coordinator. This is especially important for patients in the advanced stages.

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E. TEAM MEETINGS

RECOMMENDATIONS

- The team gets together in face-to-face or virtual team meetings at least once a month.
- Team meetings are used mainly for goal-setting in patient care, for education, to talk about organizational and communication issues and to discuss complicated patients.

CONSIDERATIONS

- During team meetings, team members discuss treatment plans and jointly make integrated group decisions, especially for patients in the advanced stages of the disease.
- It is important to organize team meetings to promote team building.

F. INPATIENT OR OUTPATIENT CARE

RECOMMENDATIONS

- An outpatient setting is the preferred setting to organize care for the majority of PD patients.
- An inpatient setting is useful for more complicated patients with the need for frequent revision of the treatment plan, followed by consultations in the community to aid generalization.

CONSIDERATIONS

- Patients are referred to community healthcare professionals that are skilled in treating people with PD. There is at least annual follow-up in the clinical center.
- If necessary, e.g. due to regional unavailability or complex needs, patients are referred to healthcare professionals who practice within the clinical center.

G. TELEHEALTH

RECOMMENDATIONS

- Telehealth has added value for care delivery, especially for patients living at a great distance from the clinic, patients with a job, and advanced patients who would otherwise be lost to follow-up. In addition, telehealth can support communication between healthcare disciplines.
- Telehealth can be used by neurologists for follow-up consultations to enable video consultations and tele-rehabilitation, but not for establishing a diagnosis in new patients. For allied healthcare, the use of telehealth varies per discipline.

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Supported by the following organizations:

