

Homework before meeting with the patients (Non-exhaustive list of questions !!!)

1. Diagnosis and disease progression

- How did you first notice symptoms, and what led to your diagnosis?
- How has your disease progressed since you were diagnosed? Are there any key milestones or turning points you can share?
- What has your journey through the healthcare system been like? How have your experiences with specialists been?

2. Symptoms and management

- What motor symptoms (like tremors or stiffness) do you experience, and how do they impact your daily life?
- Do you experience any non-motor symptoms, such as mood changes, sleep issues, or cognitive changes?
- How do your symptoms vary from day to day, or at different times of day? Do you have “good” and “bad” days?
- What strategies or treatments do you use to manage your symptoms? Which have been most effective?
- Motor symptoms: What motor symptoms, such as tremors, stiffness, or slowed movements, do you experience? How do these symptoms affect your daily activities and overall mobility?
- Symptom management: What strategies or treatments do you use to manage your motor symptoms? Are there specific techniques or therapies that help?
- Non-motor symptoms: What non-motor symptoms, such as cognitive issues, mood changes, sleep disturbances, or gastrointestinal problems, do you experience? How do these symptoms impact you differently from the motor symptoms?
- Emotional and psychological effects: How do the non-motor symptoms affect your mental and emotional well-being? Are there any non-motor symptoms that have been especially challenging?
- Balancing symptoms: How do you balance the challenges of both motor and non-motor symptoms? Are there days when one type of symptom is more prominent than the other?

3. Treatment and medication experience

- What medications are you taking, and how effective have they been? Have you experienced any side effects?
- Do you use any alternative therapies or treatments, like acupuncture or herbal supplements?
- Have you considered or undergone surgical options, such as deep brain stimulation (DBS)?
- Are you involved in any clinical trials or research studies? If so, how has that experience been?

4. Impact on daily life and functionality

- How has Parkinson's impacted your ability to perform daily activities, such as dressing or bathing?
- Has your ability to move around, walk, or drive changed over time?
- Have you noticed changes in your memory, concentration, or cognitive functioning?
- How has Parkinson's affected your work or productivity? Have you made any adaptations?

5. Emotional and psychological impact

- How do you manage the emotional challenges of living with Parkinson's, like frustration or sadness?
- How has Parkinson's affected your sense of self and personal identity?
- What strategies or support systems do you use to manage stress and build resilience?
- Who are the main sources of support in your life, such as family, friends, or support groups?

6. Social and relationship changes

- How has Parkinson's impacted your relationships with family and friends?
- Has the disease affected your romantic relationships or intimacy?
- How have your caregiving needs changed over time, and how have caregivers been affected?

7. Physical activity and lifestyle modifications

- What kind of physical activities or exercises do you find helpful, and how often do you engage in them?
- Have you made any dietary adjustments to support your health?
- What challenges do you face with sleep, and how have you tried to address them?

8. Cognitive and mental health

- Have you noticed any changes in memory, focus, or problem-solving abilities?
- Do you experience challenges with mental health, like depression, anxiety, or apathy?
- What activities or strategies do you use to support your cognitive health?

9. Financial and legal considerations

- How has Parkinson's affected your finances, such as with medication or treatment costs?
- Have you experienced any challenges with health insurance or accessing healthcare?
- Have you made any legal preparations, like establishing a power of attorney or a living will?

10. Caregivers, family, and impact

- Role of caregivers: Who are your primary caregivers, and what role do they play in supporting your daily needs and health management?
- Caregiver challenges: What challenges do your caregivers face in providing support, and how do you navigate these together?
- Family dynamics: How has Parkinson's affected your family relationships? Have roles within the family changed, and how have family members adjusted?
- Emotional impact on family and caregivers: How do your family and caregivers cope with the emotional aspects of Parkinson's? Are there ways you support each other emotionally?

- Communication and understanding: How do you communicate with family and caregivers about your needs and challenges? Are there things you wish they understood better about your experience?
- Support for caregivers: Are there resources, support groups, or counseling that your caregivers find helpful? Do they have their own support network?
- Impact on social life: How has Parkinson's affected social gatherings, friendships, or family events? Have you made adjustments to maintain these connections?
- Balancing independence and care: How do you and your family find a balance between maintaining your independence and receiving the care you need?

11. Community and support involvement

- Have you participated in any support groups, and what has that experience been like?
- Are you involved in the Parkinson's community, through awareness campaigns or volunteering?
- Do you find informational resources about Parkinson's helpful? Are there any you recommend?

12. Philosophical or spiritual perspective

- How has Parkinson's changed your perspective on life or personal growth?
- Does spirituality or faith play a role in how you cope with Parkinson's?

13. Future hopes and concerns

- What are your main concerns for the future, especially as the disease progresses?
- What hopes or goals do you have for the future, such as potential treatments or personal milestones?
- Are you involved in Parkinson's advocacy or interested in advancements in research?