

## **Delivering the Diagnosis of Parkinson's Disease- Setting the Stage with Hope and Compassion**

Indu Subramanian, MD, Kuhan Bradley McDaniels, PhD, MD, Soania Mathur MD, Bart Post MD, PhD, Anette Schrag MD PhD

Department of Neurology, David Geffen School of Medicine, Los Angeles, CA, USA

Parkinson's Disease Research, Education, and Clinical Center (PADRECC), Veterans

Administration Greater Los Angeles Health Care System, Los Angeles, CA, USA

Department of Rehabilitation and Health Services, University of North Texas, Denton, TX, USA

Department of Rehabilitation and Health Services, University of North Texas, Denton, TX, USA

Unshakable MD, Toronto, Ontario, Canada

UCL Queen Square Institute of Neurology, University College London, London, UK

Delivering a diagnosis of Parkinson's disease (PD) with care and compassion requires both solid medical expertise and emotional sensitivity as it is devastating for many to receive this news. Clinical guidelines emphasize that a diagnosis of PD should be made by a movement disorders specialist (MDS).[1] This is primarily based on their expertise in making an accurate diagnosis and to initiate the most appropriate treatment. However,[2] in the current medical landscape, access to an MDS is not always possible and the initial suspected diagnosis may be made by other health professionals such as the primary care physician or community neurologist. Whilst the diagnosis may have been suspected by some people, e.g., family, friends, colleagues, with symptoms preceding the diagnosis for several years, it is typically confirmed by the medical specialist. For some, it may be the first time that a person experiencing symptoms hears about PD as the likely underlying diagnosis. The diagnosing clinician is the person who will deliver the life changing information of a disease that is chronic, progressive, and associated with numerous symptoms and long-term disability, which commonly elicits fear and uncertainty in the person receiving the news. Because of the significant emotional impact, many patients vividly remember their diagnosis and how it was delivered many years later. Being mindful of the shock of this diagnosis and how the information is delivered while considering what patients find difficult or comforting in the messaging is, therefore, the key to providing the best possible experience for patients at this crucial time.

**Considerations when Delivering a Diagnosis of Parkinson's (Fig1)**



Fig 1- Important Considerations for Getting the Diagnosis of PD (NMS-non-motor Symptoms)

## Making the Diagnosis of PD

“10 years on, I can still recall how the clouds looked that fatal day. I can describe the sounds of the traffic. The smell in the air... I remember the chilling silence of the waiting room too. Then I remember the look in her eyes.. and most of all I remember the exact words she used-‘You’re exhibiting symptoms of Parkinsonism’.... So scripted. So rehearsed in the words she used. Like it had been taught from a handbook in year 1 of MDS school. Like she had said it a 100 times before.”

## Delays in Diagnosis/Care

Despite the presence of symptoms, many patients may have waited months or years to see the doctor, 30% may have waited one year or more. Symptoms may be non-specific or even point to other diagnoses, reflecting a pre-diagnostic phase of the disease that can be 10 years or more. [3]This also makes a diagnosis at the initial visit for non-specific or non-motor symptoms difficult for physicians and the delay from initial symptoms to diagnosis has been reported to be as long as 10 years. [4]

## Diagnostic Accuracy at Presentation

Even once more typical features of PD occur, making a diagnosis of PD can be difficult particularly in the early stages, and many patients may have a series of visits over months or a year before they are given a diagnosis. Even when a diagnosis is made, uncertainty may persist. In an analysis of 20 studies, including 11 using the gold standard of pathologic examination, the

diagnostic accuracy of PD diagnosis when made by non-experts was 73.8% vs. 79.6% when made by an MDS at initial assessment but rose to 83.9% at follow-up. Using the UK Parkinson's Disease Society Brain Bank Research Center criteria[5], the pooled diagnostic accuracy was 82.7%. This necessitates clinicians to use caution in the initial diagnosis to avoid giving an incorrect diagnosis and also results in unsettling uncertainty for patients looking for a firm diagnosis. [6, 7] There are a host of reasons that make the diagnosis of PD complex including the insidious onset of symptoms and the absence of a biomarker. In one report,

As a result of these challenges, sometimes the diagnosis is delayed or missed altogether especially in younger patients, women, people of color and those who reside in rural areas. [8] Delays are also more common when tremor is absent or with lower extremity predominance. [9] 7% of patients were told there was nothing wrong with them at the first visit [10] As a result, many patients search for answers online but getting vetted information that is medically sound can prove challenging, and online searches can lead to a range of misdiagnoses and misinformation.

### **Under Recognition of Non-motor symptoms/ Mental health**

Despite being classified as a motor disease, PD is also associated with a variety of non-motor and mental health features, which contribute to reduced quality of life often more than the motor features.[11] [12] As PD is still considered primarily a motor disease the heterogeneous non-motor features are often undervalued and go unrecognized from diagnosis.[13] These issues like depression, anxiety, apathy and sleep dysfunction are often hidden and difficult to identify without specific probing despite being common.[14] Some patients with PD experience prodromal depression and can present with depression at diagnosis that, when addressed, can improve long-term outcomes.[15] Hence, many patients suffer in silence while their doctors may focus on more visible symptoms like tremor or slowness. In fact, many non-specialized physicians may not even be aware of the complexity of PD and the significant non-motor burden. In medical school students may have primarily been taught about the cardinal motor symptoms of tremor, stiffness, slowness and gait issues, emphasizing an older, white, male image. In addition, with the rise of healthcare provided through allied non-physician care providers who may not have had any formal education on PD, there is a pressing need to increase awareness of this complex disease in both society and in medical education.

*"I get that the diagnosis discussion, much like the condition itself, is a balancing act (too much information would have been overwhelming, too little would have been unhelpful) but in a way, if I was told more about the array of symptoms at that point I think I would have taken some comfort. Why? Purely because I had been exhibiting many of symptoms like anxiety, low mood, fatigue, low blood pressure, constipation, sleep issues etc. for many years. Yes the future was uncertain but here was an opportunity to answer questions about the past and present. Years later when I learnt more about these 'hidden' symptoms, it was a eureka moment. Everything started to make sense. I wish I had that opportunity on 'D-day' itself."*

### **Portrayal of the "typical" PD patient**

In the media and popular opinion today, PD continues to be represented as a motor disease of white, old men. Similarly, the images we use to teach medical students are drawings typically depicting older white men, drooling and hunched over, in a wheelchair or using a walker.[16] However, many patients with PD worldwide who do not fit this stereotype, and many PWP who are younger, or female or who are from a different race have their diagnoses delayed or missed altogether as a result. In a survey, some felt their ethnic community did not understand them and had misconceptions like “You’re black, and black people don’t get PD.” An Indian PWP hid her diagnosis because she feared how people would react. She did not want people to feel pity for her or cause shame or embarrassment to her family and was pressured to hide the disease from her community. [17, 18] The inaccurate assumption that PD only occurs in old age has three negative consequences: (i)The diagnosis of PD is often missed entirely or delayed in younger people; (ii) There is a misconception that PD symptoms such as slowing, stiffness or tremor are a natural consequence of aging; and (iii) Ageism (discussed below).

“Looking back it's become clear that I experienced 3 unintended biases that led to a year-long delay in making the diagnosis: An age bias, a race bias and a symptom bias. Collectively I didn't fit the bill of the Parkinson's stereotype. Ironically if the dots were connected and my early non motor symptoms were taken into account... I was the text book definition of a person with Parkinson's.”

The diagnostic difficulties typical of the initial phase of PD can lead to a long delay and uncertainties with significant impact on PwP's experiences, with a wish for an earlier and clear answer for many.

“What did Parkinsonism even mean? Do I have Parkinson's or not?! I didn't want another wild goose chase. I wanted clarity, not 'isms' “

“The MDS had a visible smile on her face, when I returned 2 weeks after starting on the medication...‘You've responded well'. But her positive manner was just reflecting the final confirmation. She was pleased with herself and validation of early initial diagnosis. I didn't begrudge her that. There is nothing 100% conclusive in initial diagnosis after all and in her eyes I was 'better' than a fortnight prior. Yet at that moment, her smile was mirrored by my frown.”

### **Emotions at the time of diagnosis**

When the diagnosis is made, this is typically associated with a host of negative emotions. See fig 2

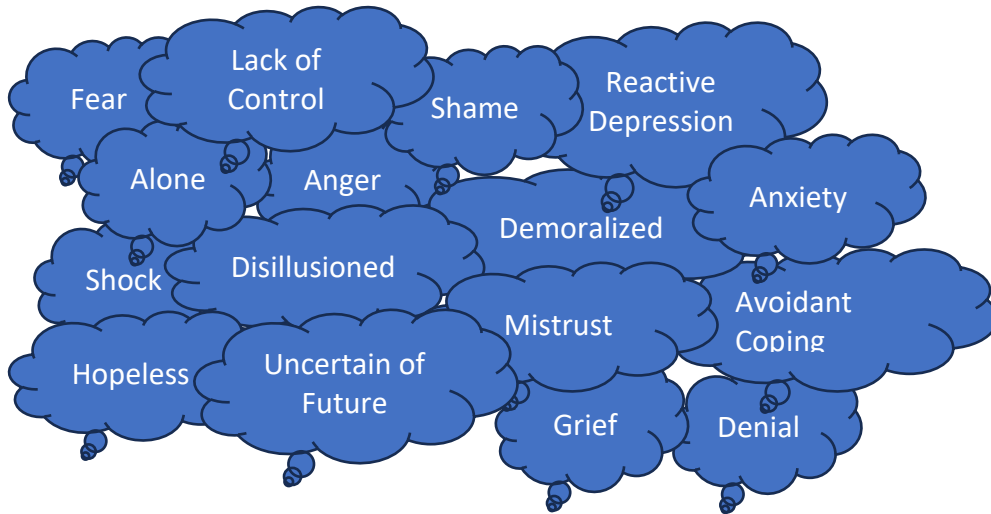


Fig 2: Possible Negative Reactions experienced by PWP when given the Diagnosis of PD

### Challenges in Acceptance:

Getting a PD diagnosis can take time to accept and represents one of the first “transitions” in the journey of people with Parkinson’s (PWP). [19] [7, 20] An analysis of 20 studies looking at the subjective experience of living with PD described challenges associated with disease awareness, life disruption, adjustment, the fluid relationship with their external environment and the changing self. The authors describe PD as a transformative journey wherein the PWP uses strategies to stabilize their changeable relationship with their external environment while simultaneously redefining their concept of self. [19, 20] There is a continuous process of adjustment of the concept of self by “discarding old and re-discovering new activities and traits” that are central components of a quality life. In one of the models of psychosocial adaptation to chronic illness (the Disability Centrality Model)[21], Bishop contends that when people lose the ability to engage in activities they deem central to their well-being, they have poorer quality of life outcomes. Many PWP describe getting the diagnosis almost akin to a traumatic event such as the loss of a loved one. [22, 23] There may be stages like those described in classic grief that a patient goes through. Shock, anxiety, denial, depression and anger have been described as common reactions to a chronic illness diagnosis, but questions persist regarding whether they are linear or pendular and when in the process that they occur.[24] Denial is among the most troublesome reactions as it can lead to not seeking care or not following up with the health care team, putting off starting a treatment that could improve day-to-day functioning. Furthermore, it is important to start lifestyle measures (eg exercise) that could positively impact Parkinson’s disease symptoms. There is still a debate whether lifestyle intervention can really postpone milestones of disease progression.[25] In some communities where there may be additional barriers of mistrust or language, these delays can be magnified. We have seen that in some PWP who are African American or Hispanic delays in seeking and “accepting” care can be quite striking and may lead to a false perception of “non-compliance” on the patient’s part and treatment biases that can then complicate the doctor-patient rapport and lead to negative outcomes for these patients. [26] See Fig 2

## Uncertainty of Future

Presentation and progression of PD is heterogeneous, resulting in variability in the lived experience for each PWP. Because of this uncertainty and patient's inclination to compare themselves to their peers, patients may catastrophize, which may result in significant anxiety. This fear of the unknown or uncertainty of the future can be unsettling, and unsuccessful coping strategies can lead to depression, demoralization and a general unease about the future.[27] Though there may be ways to predict prognosis and disease progression by assessing symptoms and individual characteristics at certain stages of the disease (eg older age, non-levodopa responsive motor symptoms, postural instability, cognitive symptoms may have worse outcomes in general), whilst highlighting characteristics with better prognosis may be beneficial, revealing negative predictors may not be desirable.[28-30] Furthermore, there is considerable variability in PD symptoms and progression making predictions unreliable. Instead, there is a need to emphasize individual variability to avoid comparison with other, often negative images of PD and its progression. With our current knowledge, predicting progression is not recommended for the individual PWP.

*"Everyone's Parkinson's journey is different – the message needs to be hammered home from day 1 to resist the human temptation to compare with others"*

However, the uncertainty in predicting the future may be unsettling and difficult to accept.

*"I was left disillusioned. I felt nobody could give me straight answers. Trust in the medical profession was somewhat eroded. I think that's partly the reason it took me several years before I started participating in research and clinical trials"*

The plethora of symptoms that can be present in early PD may not have been associated with such a diagnosis, and revealing this association may be beneficial and can come as somewhat of a relief.

## Stigma

Difficulty in accepting the diagnosis is often also associated with the stigma that is associated with PD. This is perhaps particularly so in younger age groups and particular cultures.

### Self-Stigma

PWP have described feeling shame about their diagnosis. There may be embarrassment about some of the symptoms and a decreased sense of confidence. Many PWP keep their diagnosis a secret and may hide their disease from even their closest loved ones and people they care about to avoid feelings of inferiority. Hiding the disease may lead to guilt, isolation and avoidance of social interactions. These negative reactions can lead to increased self-hate and a lack of self-compassion. The perceived change in the role in the family and in society can be stressful especially in younger PWP as they may fear losing their job There is a fear that their spouse may leave them or that they will not be able to provide financially for their family. Women have described feeling inadequate due to an inability to perform domestic duties or act as a caregiver

for others.[31] . They may feel a difference in their body image, and women living with PD (WwP) have described a loss of femininity. [31, 32] Many family members have described feeling left out and cut off from the person living with PD. It becomes the “elephant in the room” – something that is never discussed. The PWP feels a tremendous weight of their secret, and this can add to more stress and worse mental health consequences. The loneliness and isolation created can have devastating consequences such as depression and anxiety for the PWP and for the people who love them. [33, 34]

“The isolation, the anger, the confusion, the sorrow, the mistrust, the denial, all made worse and prolonged because of that traumatic period. I became one of the silent majority in the PD community, who shut off from the world for many years.”

The inaccurate assumption that PD only occurs in old age has the further consequences of Ageism (discrimination against older members of society) which contributes to the stigma associated with PD, and PWP psychologically associate themselves with this stigmatized group. Stigma increases isolation, which is associated with increased depression and anxiety that directly and negatively impact quality of life and disease outcomes. Because of the stigma associated with PD, many PWP who are doing well and thriving may not come forward to tell others about their disease for fear of discrimination. The prevailing conception of PD automatically includes the most severely affected cases and the ones with the most significant disability, thus propagating stigma and the associated negative reactions to those who don't fit the stereotype. [35]

### **False Beliefs**

Throughout the world, false beliefs persist that contribute to the stigma of PD. In sub-Saharan Africa, PD symptoms have been attributed to “witchcraft” or “curses”. [36] In Uganda, PD is believed to be both contagious and a form of insanity. [37, 38] Another misconception is that PD is a disease that happens to people who have done something to cause it. Perhaps there is a sense in society that the PWP is a drug abuser or intoxicated [39] as those symptoms may mimic the motor symptoms of PD. This stigma has been described more in younger PWP because they do not fit the typical presentation of PD. As parkinsonian symptoms can occur as drug-induced phenomena in patients who are on antipsychotics in people living with mental illness, there can be a negative association with PD features. This stigma has been described more in younger PWP because they do not fit the typical presentation. This sense of devaluation by others or negative assumptions is “perceived stigma” where the PWP may *feel* that they will encounter negative reactions from people if their diagnosis is exposed. This stigma can lead to worse self-esteem, depression, anxiety and less seeking of health care. [40, 41]

“It's not my fault. It's the luck of the draw. It's not something I did or didn't do”

### **Communication of Diagnosis**

Many PWP have spoken about the day that they received their diagnosis as a traumatic experience, some describing it as one of the worst moments of their lives.[10] Many were alone when they received the news and their recollection of that day is often of feeling hopeless, demoralized and depressed. When a group of patients was surveyed about the time of their diagnosis, 30% of patients were given the diagnosis during their first meeting with the doctor, 50 % felt it was given with a lack of sensitivity, 12% didn't feel that there was time for questions, 28% felt unable to ask questions at that visit and 50% of patients reported that they were not given information about non-pharmacological approaches such as physiotherapy or exercise.[10] Too often, they left the office with just a prescription in hand and a lack of understanding of other treatment options. Some have described feeling disconnected from the person giving them the news. Whether this was a reaction [42]to the news itself or a true recollection of the events that took place, it is clear that we have to do better with delivering the diagnosis with compassion and providing supportive guidance about next steps. The way the diagnosis is given may impact both quality of life and satisfaction with care [10, 43]. Flexibility and active listening while patiently addressing patient questions is important but limited by time constraints in many clinics and is unlikely to be sufficient particularly for those who were not expecting the diagnosis. Some patients may not even know what to ask at this early stage, so it is imperative for the clinician to guide them through this process and provide information that can help them better understand the disease and the steps that lie ahead.

“It wasn't that I didn't have time to ask questions at the initial consultation, I was still processing, I was in shock. That vacuum was subsequently filled by Dr Google which ultimately was to my detriment”

### Considerations in Giving the Diagnosis of PD (Fig 3):





Fig 3- Important Considerations for Giving the Diagnosis of PD

### Finding the Right Words

Using appropriate terminology at the time of diagnosis is crucial, as being told that they have PD may for some be equated with becoming wheelchair bound and early death [44] There has been a concern that clinicians use terminology like the “honeymoon phase” of PD which may be patronizing to PWP and underestimate the true burden of getting the diagnosis. [44] Research from patients with dementia indicate that it is critical for providers to balance “truth telling” with “hope.”[45] Additionally, clinicians should avoid implicit language and the use of euphemisms, which relying on the patient to form interpretations and draw their own conclusions, which may be problematic for many patients.[46, 47] Clear and considerate communication is essential to ensure that the PWP understands what is being delivered and feels cared for. [48] See Table 1

| Table 1: Practical Tips for Delivering the Diagnosis  |
|---|
| Quiet Private Space   |
| Ensure Adequate Time  |
| Have PWP Come with Care partner/ Confidante   |
| Explore Knowledge/Expectations/Fears  |
| Assess Perceptions/Stigma/ False Beliefs  |
| Assess Interest in getting Info- timely vs early?   |
| Avoid overwhelming with information -consider spreading information over 2 or more appts    |
| Adjust to the person’s current situation, expectation and fears and be culturally sensitive |
| Ask what they have Understood/ Repeat   |
| Provide written information and reliable information resources                              |
| Allow PWP and their family to express emotion/ Give space for reactions                     |
| Normalize reactions of stigma, grief, shame, avoidance, demoralization                      |
| Respond with compassion and appropriate emotion-be present                                  |
| Avoid being patronizing, using terms like “honeymoon”                                       |
| Make PWP feel seen and heard  |
| Proactively ask about concerns/questions in this early phase                                |
| Be Positive – Give Hope   |
| Allow the PWP to have agency and to personalize their own hope                              |
| Foster curiosity and be open-minded   |
| Educate around possible linked Mental health/ Non-motor symptoms                            |
| Offer bespoke Wellness/ lifestyle choices   |
| Empower- Signpost options for Self-management   |
| Assess resources/accessibility of lifestyle & wellness choices                              |

|   |
|---|
| Provide Structure/Stability/Schedule  |
| Identify the point person of communication on medical team  |
| Communicate with the Health Care Team especially the Primary Care Provider                                    |
| Offer appt in 4-6 weeks and a clear plan for future follow up   |
| Engage the Multidisciplinary Team   |
| Communicate with the Health Care Team including Primary Care Explore and consider the person's support system |
| Stress the Importance of Social Support   |
| Consider Referral to Support Group  |
| Become trauma informed  |
| Assess tele-resources of PWP- tech savviness/ computer/ internet  |

### What PWP Want at diagnosis

Multiple factors have been proposed that help PWP to achieve good QoL.[49] They include quality healthcare delivered through a patient-centered approach to address the most bothersome and impactful symptoms. [50, 51]They want guidance on self-care regimens and education for themselves, their families and health care professionals on the disease, the symptoms, how to recognize them, new treatment options, coping strategies and available lifestyle choices. The information needs to be clear and understandable and delivered in an honest and transparent manner. They want support from family and community, and central to both these relationships and good QoL is the ability to communicate without deficit and to feel accepted. [52]

In a survey of PWP, Schrag et al found that some PWP wanted to get all the information from their physician, while others prefer to look information up on their own or have gotten information from their family who may advocate for them. [10, 17, 53]Some patients reported wanting to know now about their future possibilities while others felt it better to not know about everything or to be exposed to more advanced symptoms in patients at support groups. Patients wanted practical and positive information to manage day-to-day issues, wanted information on approaches outside of pharmaceutical management and especially valued information on lifestyle approaches such as exercise, stress reduction techniques, physiotherapy and diet. [17]Although PWP and their families felt exercise could benefit general emotional well-being and physical health outside of PD, when asked about barriers to self-management such as exercise, PWP included hearing issues, being embarrassed or self-conscious of their motor issues, a lack of resources, low self-efficacy and a lack of digital skills. There was also a concern that their lack of digital skills could lead to confidentiality breach or mistakes using telehealth or digital technology. [10, 17] Patients were interested in information about more integrative approaches

including supplements, probiotics or mucuna, or CBD but often did not bring this up with their doctors. [17]

### **Bespoke Cultural Context**

The difference in culturally specific needs must be taken into consideration. There should be an emphasis on being culturally sensitive as culture can significantly affect how people process, perceive and respond to the news. PWP from diverse cultural backgrounds surveyed in the UK wanted simple videos demonstrating instructions for PD management translated into different languages and to see diverse [10]representation in the PWP portrayed so that they could relate to people who looked like them. Ensuring that communication aligns with the cultural context can foster a more empathetic, respectful and positive interaction thereby creating a safe and supportive environment to process their PD diagnosis. Universally, patients were positive in their outlook and were hopeful for a cure, which motivated them to participate in research. [10]Patients reported that support from their family, friends and faith-community was key. Referral to another PWP of the same age group or an age-appropriate Parkinson Support group had also been proposed. [10]

Looking back now, so much of that prolonged diagnosis period makes sense now. It's wonderful what 10 years of hindsight gives you. I wish I had 'future me' to guide me, during what proved to be the most traumatic time in my PD journey...and in my life.

### **Delivering the Diagnosis:**

"I've begun to empathize with the messenger. What must it be like to deliver the news and yet be unable to answer the most basic of questions 'why, how, when'. "

From a clinician standpoint, there can be a reticence in giving bad news. "Bad news" is defined as "situations where there is either a feeling of no hope, a threat to a person's mental or physical well-being, a risk of upsetting an established lifestyle, or where a message is given which conveys to an individual fewer choices in his or her life." [54]In other disease states, it has been shown that bad news when communicated poorly ends up causing confusion, long-term distress and resentment and if done well, can enhance acceptance, adjustment and understanding.[54, 55] There has been more recent interest in delivering bad news in neurology but most of our current understanding is from the cancer literature. [56-58] A recent review on delivering the diagnosis of PD includes anecdotes and wisdom and reviews some practical tips. [59, 60]They included (i) perception or previous experience with PD (ii) health literacy (iii) cultural background and preferences (iv) ability to access specialized care (v) social support network as important. They describe using the SPIKES method of delivering the diagnosis. [61]. SPIKES is a six-step protocol for delivering bad news designed for the clinicians in the oncology setting by Bailes et al in 2000 but has been recently adopted for PWP.

General advice on delivering "Bad news" includes finding a quiet place, ensuring adequate time and allowing/recommending for a caregiver to be present. [62]It may help to spread out the delivery of the news to a second appointment where the patient is told to bring in a loved one,

but in person delivery is key. It is important to assess what the patient already knows and to ask them if it is okay to deliver more information while allowing them to dictate the flow of information. Instilling hope and allowing the patient to express their discomfort and fear are critical.

### **A Specific Word on Hope**

Hope is a substantiated expectation that one can influence their own future in a positive way. [63, 64]The concept of delivering hope that is personalized to the patient and allowing them to be an agent of their own hope has been discussed by Noordegraaf et al. with a strong patient voice advocating for the following: “Sooner or later, PWP will need to develop their own personalized hope narratives, with ingredients they can feed themselves on a daily basis. For the beauty of hope is that it simply cannot be delegated. Not without losing its form and strength.” [65]They quote a person living with ALS “Once you put the responsibility of your fate in the hands of an outside force, you are out of the game”. [66] They discuss utilizing the Multidisciplinary team (MDT), facilitating disease literacy and education, pointing to options for self-management and having the clinician “sit back and tune in.” They also discuss using diaries and wearable sensors in a way to track disease and personalize self-management. [67]

After the information is presented, it is helpful to assess patient understanding and then to re-iterate the message again at the end of the visit. Providing the patient with a written summary of the points discussed is also valuable. Being culturally informed and providing support that is mindful of language, resources of the patient, their ethnic background and religious beliefs is key. Patients have reported that they would like information presented by someone who is truthful, compassionate and caring. [68]We may be able to learn from the delivery of a dementia diagnosis, to help guide better practices with PWP.[69] Providing follow-up appointments in close proximity with a team member to be available for questions and further sign-posting is essential.

“I walked out of the hospital that day after the initial diagnosis, with nothing other than a prescription in hand. I was left with no information, no referral, no sign posting. Nothing. I was given no advice on benefits of exercise or other holistic treatments until many years later”

“Diagnosis is a process, not necessarily a single event or point in time. For 1 in 3 diagnoses take over a year. Support services typically start from point of final diagnosis, they should be available from initial / suspected diagnosis”

### **Timely Diagnosis**

In a disease like PD, the notion of giving an early diagnosis may not be the same as giving a “timely diagnosis” – this concept has been explored in Alzheimer’s literature and has had some recent attention in PD. “Timely” recognizes both the potential advantages and the disadvantages of an earlier diagnosis and respects the priorities and wishes of the PWP as central to when this should occur. The decision about how much or how little information to share with the patient should be personalized collaboratively with the patient while considering the PWP’s understanding of their condition, their goals, fears, potential benefits and possible harms.

[53]The pillars of medical ethics including autonomy, beneficence, non-maleficence and justice should be preserved. [59]Accordingly, the lack of disease modifying therapy in the current treatment landscape leads to reliance on waiting to treat with symptomatic therapies. Non-pharmacological approaches such as exercise[70] pose an important option that may soon prove to be disease modifying and may change the treatment landscape and would be an example of beneficence supporting “early” diagnosis. Whereas the non-maleficence approach may aim to delay diagnosis to delay the risk of causing social or psychological harm through diagnosis. The review by Rees et al outlines the need to individualize the “time” of diagnosis for the PWP ranging from some who would want to know as soon as possible to some who would never want to know but emphasizing the prodromal vs symptomatic timelines where the presence of disease modifying therapies could make a big difference in the “timeliness.” [53]

### **The Role of the Clinician/Multidisciplinary Team**

In the dialectical model described by Rutten et al, the role of the neurologist and the allied health professionals are complementary.[20] They describe the neurologist as the educator and the other members of the multidisciplinary team such as the nurse, psychologist or social worker as supportive agents who help the PWP adjust to their diagnosis. They also emphasize the reciprocity of the PWP and the clinician in working together to redefine stability with the clinician helping to treat symptoms and minimize disruption and the PWP being actively engaged and giving input on what defines stability and their concept of self. They conclude by saying that they “advocate for a multi-disciplinary treatment approach for PD which is holistic, dynamic, and participatory.” [20]Using a wellness approach where patients are empowered and given structure in their lives through daily lifestyle choices is one way to allow the patient to regain a sense of agency and control. [71]Additionally, there has been a call to remove terminology such as “honeymoon phase” and for conversations between health care professionals and persons with PD to be symmetrical and not patronizing. Alonso- Canovas et al feel that removing this term may lead to “more respectful and honest communication with patients” and act as a reminder to physicians to both clinicians to ask and PWP to not conceal, even unconsciously, their problems at this early stage of disease. [44]

Whilst regular and flexible appointments with an MDS or their team would be desirable, many PWP do not have access to subspecialists in movement disorders and many do not even get to see a neurologist for their PD management often for years into their disease. With the increased demands on the health care system, shortage of providers and limited resources, it becomes critical for patients and their families to become educated, empowered and to advocate for themselves throughout the journey with Parkinson’s, beginning with diagnosis.

The delivery of a PD diagnosis is a pivotal moment in the patient’s journey, and its significance can’t be overstated. The manner in which the diagnosis is communicated has far-reaching implications for the physical, emotional and psychological well-being of the patient throughout their PD trajectory and for their lifetime. As such, it is imperative for healthcare professionals to recognize the importance of their role in delivering a PD diagnosis. Implementing patient-centered communication strategies such as empathy, active listening and providing clear and complete information can make a profound difference in how the diagnosis is received. As we

move forward in our efforts to improve the lives of PWP, let us remember that a new life begins with the diagnosis. By acknowledging the importance of how the diagnosis is delivered, we take a critical step toward fostering hope and improving quality of life for those affected. The time has come for cautious hope instead of conservative paternalism.

“My ‘D-Day’ experience shaped so much of the years that followed. It contributed to my denial, my isolation and left me feeling helpless. It haunts me to this day and i see it echoed amongst the newly diagnosed i meet now. Talk of a ‘honeymoon’ period just left me with a sense that the clock was ticking. A countdown to a fate i couldn’t control. Granted, there is no right way to deliver a Parkinson’s diagnosis ..but surely we can do better than this.”

1. Stewart, D.A., *NICE guideline for Parkinson's disease*. Age Ageing, 2007. **36**(3): p. 240-2.
2. Weintraub, D., et al., *The neuropsychiatry of Parkinson's disease: advances and challenges*. Lancet Neurol, 2022. **21**(1): p. 89-102.
3. Schrag, A., et al., *Prediagnostic presentations of Parkinson's disease in primary care: a case-control study*. Lancet Neurol, 2015. **14**(1): p. 57-64.
4. Kis, B., et al., *Novel three-stage ascertainment method: prevalence of PD and parkinsonism in South Tyrol, Italy*. Neurology, 2002. **58**(12): p. 1820-5.
5. Hughes, A.J., et al., *Accuracy of clinical diagnosis of idiopathic Parkinson's disease: a clinico-pathological study of 100 cases*. Journal of Neurology, Neurosurgery & Psychiatry, 1992. **55**(3): p. 181-184.
6. Gaenslen, A., et al., *The patients' perception of prodromal symptoms before the initial diagnosis of Parkinson's disease*. Mov Disord, 2011. **26**(4): p. 653-8.
7. Bloem, B.R., M.S. Okun, and C. Klein, *Parkinson's disease*. Lancet, 2021. **397**(10291): p. 2284-2303.
8. Rana, A.Q., I. Siddiqui, and M.S. Yousuf, *Challenges in diagnosis of young onset Parkinson's disease*. J Neurol Sci, 2012. **323**(1-2): p. 113-6.

9. Ruiz-Lopez, M., et al., *Diagnostic delay in Parkinson's disease caused by PRKN mutations*. Parkinsonism Relat Disord, 2019. **63**: p. 217-220.
10. Schrag, A., et al., *Patient experiences of receiving a diagnosis of Parkinson's disease*. J Neurol, 2018. **265**(5): p. 1151-1157.
11. Chaudhuri, K.R., D.G. Healy, and A.H. Schapira, *Non-motor symptoms of Parkinson's disease: diagnosis and management*. Lancet Neurol, 2006. **5**(3): p. 235-45.
12. Marinus, J., et al., *Risk factors for non-motor symptoms in Parkinson's disease*. Lancet Neurol, 2018. **17**(6): p. 559-568.
13. Pontone, G.M., et al., *Integration and Extension of Specialty Mental Healthcare Services to Community Practice in Parkinson Disease*. Am J Geriatr Psychiatry, 2019. **27**(7): p. 712-719.
14. Soh, S.E., M.E. Morris, and J.L. McGinley, *Determinants of health-related quality of life in Parkinson's disease: a systematic review*. Parkinsonism Relat Disord, 2011. **17**(1): p. 1-9.
15. Pontone, G.M. and K.A. Mills, *Optimal Treatment of Depression and Anxiety in Parkinson's Disease*. Am J Geriatr Psychiatry, 2021. **29**(6): p. 530-540.
16. Armstrong, M.J. and M.S. Okun, *Time for a New Image of Parkinson Disease*. JAMA Neurol, 2020.
17. Nimmons, D., et al., *Exploring the experiences of people and family carers from under-represented groups in self-managing Parkinson's disease and their use of digital health to do this*. Digit Health, 2022. **8**: p. 20552076221102261.
18. van der Eijk, M., et al., *Moving from physician-centered care towards patient-centered care for Parkinson's disease patients*. Parkinsonism Relat Disord, 2013. **19**(11): p. 923-7.
19. Read, J., et al., *Transitions and challenges for people with Parkinson's and their family members: A qualitative study*. PLoS One, 2022. **17**(7): p. e0268588.
20. Rutten, S., et al., *The Subjective Experience of Living with Parkinson's Disease: A Meta-Ethnography of Qualitative Literature*. J Parkinsons Dis, 2021. **11**(1): p. 139-151.
21. Bishop, M., *Quality of Life and Psychosocial Adaptation to Chronic Illness and Disability: Preliminary Analysis of a Conceptual and Theoretical Synthesis*. Rehabilitation Counseling Bulletin, 2005. **48**(4): p. 219-231.
22. Phillips, L.J., *Dropping the bomb: the experience of being diagnosed with Parkinson's disease*. Geriatr Nurs, 2006. **27**(6): p. 362-9.
23. Anestis, E., et al., *Giving and receiving a diagnosis of a progressive neurological condition: A scoping review of doctors' and patients' perspectives*. Patient Educ Couns, 2020. **103**(9): p. 1709-1723.
24. Livneh, H. and R.F. Antonak, *Psychosocial Adaptation to Chronic Illness and Disability: A Primer for Counselors*. Journal of Counseling & Development, 2005. **83**(1): p. 12-20.
25. Fricchione, G.L., *Clinical Implications of Illness Denial*. Psychother Psychosom, 2023: p. 1-3.
26. Dahodwala, N., et al., *Prevalence and Correlates of Anti-Parkinson Drug Use in a Nationally Representative Sample*. Mov Disord Clin Pract, 2017. **4**(3): p. 335-341.
27. Boswell, J.F., et al., *Intolerance of uncertainty: a common factor in the treatment of emotional disorders*. J Clin Psychol, 2013. **69**(6): p. 630-45.
28. Post, B., et al., *Young Onset Parkinson's Disease: A Modern and Tailored Approach*. J Parkinsons Dis, 2020. **10**(s1): p. S29-s36.

29. Post, B., et al., *Prognostic factors for the progression of Parkinson's disease: a systematic review*. *Mov Disord*, 2007. **22**(13): p. 1839-51; quiz 1988.
30. Velseboer, D.C., et al., *Development and external validation of a prognostic model in newly diagnosed Parkinson disease*. *Neurology*, 2016. **86**(11): p. 986-93.
31. Subramanian, I., et al., *Unmet Needs of Women Living with Parkinson's Disease: Gaps and Controversies*. *Mov Disord*, 2022. **37**(3): p. 444-455.
32. Mathur, S., et al., *Self-Image in Women with Parkinson's Disease*. *J Parkinsons Dis*, 2023. **13**(3): p. 329-332.
33. McDaniels, B. and I. Subramanian, *Social isolation, loneliness and mental health sequelae of the Covid-19 pandemic in Parkinson's disease*. *Int Rev Neurobiol*, 2022. **165**: p. 197-227.
34. Subramanian, I., J. Farahnik, and L.K. Mischley, *Synergy of pandemics-social isolation is associated with worsened Parkinson severity and quality of life*. *NPJ Parkinsons Dis*, 2020. **6**: p. 28.
35. Bos, A.E.R., et al., *Stigma: Advances in Theory and Research*. *Basic and Applied Social Psychology*, 2013. **35**(1): p. 1-9.
36. Fothergill-Misbah, N., *The lived experience of stigma and parkinson's disease in Kenya: a public health challenge*. *BMC Public Health*, 2023. **23**(1): p. 364.
37. Mokaya, J., W.K. Gray, and J. Carr, *Beliefs, knowledge and attitudes towards Parkinson's disease among a Xhosa speaking black population in South Africa: A cross-sectional study*. *Parkinsonism Relat Disord*, 2017. **41**: p. 51-57.
38. Kaddumukasa, M., et al., *Knowledge and Attitudes of Parkinson's Disease in Rural and Urban Mukono District, Uganda: A Cross-Sectional, Community-Based Study*. *Parkinsons Dis*, 2015. **2015**: p. 196150.
39. Moore, S., *Beliefs and Knowledge about Parkinson's Disease*. *E-Journal of Applied Psychology*, 2006. **2**.
40. Hatzenbuehler, M.L., J.C. Phelan, and B.G. Link, *Stigma as a fundamental cause of population health inequalities*. *Am J Public Health*, 2013. **103**(5): p. 813-21.
41. McDaniels, B., et al., *Staying hidden: The burden of stigma in PD*. *Parkinsonism Relat Disord*, 2023: p. 105838.
42. Dogan, B., et al., *The relationship between temperament and depression in Parkinson's disease patients under dopaminergic treatment*. *Psychogeriatrics*, 2019. **19**(1): p. 73-79.
43. *Factors impacting on quality of life in Parkinson's disease: results from an international survey*. *Mov Disord*, 2002. **17**(1): p. 60-7.
44. Alonso-Canovas, A., et al., *The Early Treatment Phase in Parkinson's Disease: Not a Honeymoon for All, Not a Honeymoon at All?* *J Parkinsons Dis*, 2023. **13**(3): p. 323-328.
45. Begley, A. and B. Blackwood, *Truth-telling versus hope: a dilemma in practice*. *Int J Nurs Pract*, 2000. **6**(1): p. 26-31.
46. Del Vento, A., et al., *An experimental investigation of the dilemma of delivering bad news*. *Patient Educ Couns*, 2009. **77**(3): p. 443-9.
47. Phillips, J., et al., *Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice*. *Br J Gen Pract*, 2012. **62**(601): p. e546-53.
48. Bor, R., et al., *The meaning of bad news in HIV disease: Counselling about dreaded issues revisited*. *Counselling Psychology Quarterly*, 1993. **6**(1): p. 69-80.



49. Andrejack, J. and S. Mathur, *What People with Parkinson's Disease Want*. J Parkinsons Dis, 2020. **10**(s1): p. S5-s10.
50. Soh, S.E., et al., *Determinants of health-related quality of life in people with Parkinson's disease: a path analysis*. Qual Life Res, 2013. **22**(7): p. 1543-53.
51. Uitti, R.J., *Treatment of Parkinson's disease: focus on quality of life issues*. Parkinsonism Relat Disord, 2012. **18 Suppl 1**: p. S34-6.
52. Takahashi, K., et al., *Quality of life in people with Parkinson's disease: the relevance of social relationships and communication*. J Phys Ther Sci, 2016. **28**(2): p. 541-6.
53. Rees, R.N., et al., *An early diagnosis is not the same as a timely diagnosis of Parkinson's disease*. F1000Res, 2018. **7**.
54. Fallowfield, L. and V. Jenkins, *Communicating sad, bad, and difficult news in medicine*. Lancet, 2004. **363**(9405): p. 312-9.
55. Kim, M.K. and A. Alvi, *Breaking the bad news of cancer: the patient's perspective*. Laryngoscope, 1999. **109**(7 Pt 1): p. 1064-7.
56. Lemmon, M.E. and R.E. Strowd, 3rd, *Right Brain: Breaking bad news: Communication education for neurology trainees*. Neurology, 2016. **87**(24): p. e285-e287.
57. Watling, C.J. and J.B. Brown, *Education research: communication skills for neurology residents: structured teaching and reflective practice*. Neurology, 2007. **69**(22): p. E20-6.
58. McCluskey, L., D. Casarett, and A. Siderowf, *Breaking the news: a survey of ALS patients and their caregivers*. Amyotroph Lateral Scler Other Motor Neuron Disord, 2004. **5**(3): p. 131-5.
59. Dhedhi, S.A., D. Swinglehurst, and J. Russell, *'Timely' diagnosis of dementia: what does it mean? A narrative analysis of GPs' accounts*. BMJ Open, 2014. **4**(3): p. e004439.
60. Saint-Hilaire, M.H. and C.A. Thomas, *Delivering a Diagnosis of Parkinson's Disease and Parkinsonism with Wisdom and Sensitivity*. Semin Neurol, 2023. **43**(1): p. 178-184.
61. Baile, W.F., et al., *SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer*. Oncologist, 2000. **5**(4): p. 302-11.
62. Ptacek, J.T. and T.L. Eberhardt, *Breaking bad news. A review of the literature*. Jama, 1996. **276**(6): p. 496-502.
63. Corn, B.W., D.B. Feldman, and I. Wexler, *The science of hope*. Lancet Oncol, 2020. **21**(9): p. e452-e459.
64. Gum, A. and C.R. Snyder, *Coping with terminal illness: the role of hopeful thinking*. J Palliat Med, 2002. **5**(6): p. 883-94.
65. Noordegraaf, M.A., S.W. van den Berg, and B.R. Bloem, *Hopamine as Personalized Medicine for Persons with Parkinson's Disease*. J Parkinsons Dis, 2023. **13**(2): p. 271-277.
66. Hamama-Raz, Y., Y. Norden, and E. Buchbinder, *The double sides of hope: The meaning of hope among amyotrophic lateral sclerosis (ALS) patients*. Death Stud, 2021. **45**(3): p. 238-247.
67. Riggare, S., et al., *Patients are doing it for themselves: A survey on disease-specific knowledge acquisition among people with Parkinson's disease in Sweden*. Health Informatics J, 2019. **25**(1): p. 91-105.
68. Warren, E., et al., *The experience of being diagnosed with Parkinson's disease*. British Journal of Neuroscience Nursing, 2016. **12**(6): p. 288-296.

69. Dooley, J., N. Bass, and R. McCabe, *How do doctors deliver a diagnosis of dementia in memory clinics?* Br J Psychiatry, 2018. **212**(4): p. 239-245.
70. Ellis, T.D., et al., *Evidence for Early and Regular Physical Therapy and Exercise in Parkinson's Disease.* Semin Neurol, 2021. **41**(2): p. 189-205.
71. McDaniels, B., et al., *A Prescription for Wellness in Early PD: Just What the Doctor Ordered.* J Geriatr Psychiatry Neurol, 2023: p. 8919887231164358.