

Social Workers in the Forefront

Providing Care to Those Living with Parkinson's



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Living with a chronic progressive illness like Parkinson's disease can pose many challenges. Social workers play a key role at a Parkinson's Center, helping persons with Parkinson's and their families to deal with those challenges, and to navigate both the health care system and the many feelings and situations that result from living with a chronic illness such as Parkinson's. Because these challenges change over the years, many families find that what worked at one point, may not be the best option at another time. Whether you are seeking help in managing changes brought on by the impact of Parkinson's, or need help finding resources—such as a support group or new housing possibilities—talking to a licensed social worker can be an important step in helping to explore new options and creative ways of living well with Parkinson's.

Persons and families living with Parkinson's disease might see a social worker for many reasons and at different points in the disease.

Some reasons might be:

- to better understand PD and to discuss reactions to receiving the diagnosis
- to talk about when and how to share the diagnosis with family and friends, or at the workplace
- to find ways to cope with feelings such as sadness, depression, anger, worries, frustration, and other feelings
- to plan for the future, including understanding advance directives, insurance issues, and home care and housing options
- to talk about and find ways to cope with loss
- to discuss changes in the family, e.g. the situation of being a carepartner for someone with Parkinson's disease
- to find ways to build or maintain good communication with a carepartner or other family members about the impact of living with Parkinson's throughout the illness
- to learn about and access resources in your local community

Social workers offer an important set of skills and are trained in the *biopsychosocial* model of assessment and care. That is, they are trained to understand that individuals and families are a composite of complex physical (biological), emotional (psychological), and social/cultural aspects, all of which combine to play a role in behavior. Some social workers are specifically trained in the unique challenges posed by Parkinson’s disease—challenges to the individual, his or her spouse or partner, and their families.

Ideally, social workers can provide the best care in a *relationship* with a person with PD and their family that is built on trust over a period of time. This allows the social worker to understand their perspective, strengths, and unique challenges—and to work *with* them to develop a plan. However, it is not uncommon that people talk with a social worker only once—for a specific issue, for information about a service, or at a point of crisis. Some persons with Parkinson’s and their families also see social workers at periodic intervals when specific needs emerge during the course of the disease.

TABLE 1

Did you know that:

- Social work degrees are awarded at the Bachelors, Masters and Doctoral levels. Most licensed social workers have a Masters in Social Work degree (MSW), which is required for the majority of social work licenses.
- All 50 states in the U.S. license social workers; however, the title “social worker” is not regulated in most states. Many persons can call themselves social workers and not have a social work degree. The best way to get clarity is to ask the person you are seeing if they are a licensed social worker. “Licensed social worker” is a regulated title, social worker is not.
- LMSW, LCSW, LGSW and LSW are typical initials you might see after a licensed social worker’s name. There are variations among the states, so ask about the licenses awarded in your state.
- The National Association of Social Workers (NASW) is the main professional association.
- In helpstartshere.org, an NASW site, you can search for a licensed social worker by state and/or zip code (see “social worker finder”).
- Licensed social work services (after sufficient supervised experience) in private practice and many other settings are reimbursable.



For example, at one NPF Center, a man with Parkinson’s and his carepartner sought counseling to deal with changes in their relationship brought about by the progression of PD. Specifically, the husband and wife both acknowledged that they were “always angry with each other.” They reported to the social worker that they neither understood the reasons for their arguments, nor ways to improve their relationship. Through the counseling relationship, the husband’s underlying depression and the carepartner’s underlying anxiety were brought into the open and explored. It became clear that the husband was feeling “down” about his increasing dependence upon his wife and his shrinking social activities. At the same time, the wife was experiencing growing anxiety about her own capacity as caregiver and about the uncertainty regarding the course of the disease. Rather than being able to identify and talk about their respective emotions, the couple found themselves “constantly arguing.” Counseling helped them to deal with their emotions. The wife gained a better understanding of her ambivalence about when and how to help her husband, when to allow him to try on his own, and most importantly, how to communicate in such instances. The man with Parkinson’s came to see how his emotional distance (part of his depression) and private anger about PD affected his wife. Counseling helped them gain a greater understanding of themselves and each other. The social worker was then able to help them communicate with each other in a more respectful and productive way. In addition, the social worker requested from the neurologist a referral for Occupational Therapy, whereby the person with PD was able to learn and to practice new techniques for dressing himself, as well as to obtain some devices that made the task easier. This social work assistance was comprised of supportive and psychological

counseling as well as a referral for rehabilitation therapy and concrete resources. It is reflective of the many situations in which a couple is struggling with changes in family relationships or roles, questions about a person's abilities, and the availability of services and resources.

Many social work interventions, whether one-time or over time, likewise incorporate the skills of listening, understanding, problem-solving, and practical concrete guidance. Another example involves a younger person, age 45, who was referred by the Movement Disorder Neurologist for counseling about her anxiety and worries about the future. She saw a clinical social worker on and off for a period of a year to discuss the diagnosis of PD and to look at options as she planned for her future. The fact that PD is so unpredictable and that no one could tell her exactly what her functioning would be like in 5, 10, or 15 years made it very difficult for her. She expressed "liking to always be in control of my life" and felt overwhelmed that PD seemed to remove this sense of control. She described herself as a "life-long worrier, even before receiving this diagnosis." Besides the individual counseling, which focused on her anxiety, the social worker recommended that she attend a support group for persons with young-onset PD. The group offered her a way to make connections with the new community, and learn about relaxation, meditation, and guided imagery techniques that others found helpful. In this case, social work counseling provided this woman with a safe environment to begin to discuss her various reactions to the diagnosis and to find ways to creatively cope with the range of feelings. Problem solving, referral to a support group, and information about resources she might need in the future were part of the care she was given. Most of all, she made a good connection to the social worker and knew that it was someone with whom she could seek further counseling in future years and as her needs changed.



TABLE 2

Healthcare settings where you can find social workers:

- medical centers
- rehabilitation centers
- adult day programs
- home health programs
- skilled nursing facilities/nursing homes
- assisted living facilities
- Veteran's Administration (VA) centers
- private practice



Couple and family stress

Parkinson's disease is a "family disease"; while one person may have the diagnosis, the whole family experiences the effects. Persons, couples, and families often seek social work services when the challenges of living with PD become very stressful and they want a trained professional to help them to more fully understand their situation and feelings, and to explore possible options.

Social workers aim to understand each person's unique situation and goals. Each situation needs to be understood, listened to, and approached in a creative way. Social work intervention is not a "one size fits all" approach. What one couple or family finds helpful may be very different for another couple. For example, one couple wants help to remain in their own home, while another couple wants help understanding assisted living options and locating an appropriate community. Furthermore, it is fairly common for one person in a couple to see a situation differently from the other, or for adult children to see things differently from one another. A woman with PD may believe that she can still travel the world, while the husband-carepartner feels quite reluctant about this. Or one adult child views Dad as "not changed at all," while the other adult child overreacts and treats Dad as helpless. These kinds of different perspectives can create new conflicts or cause old conflicts to re-emerge. The good news is that social workers are trained, experienced, and often successful in dealing with these kinds of issues. ■