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THE AMERICAN PARKINSON DISEASE ASSOCIATION, INC.

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EDUCATIONAL SUPPLEMENT #4

KEYS TO CAREGIVING

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A person close to you, someone you care for, has been diagnosed with Parkinson's disease (PD). It is natural to feel like the rug has been pulled out from under both of you. Part of coping with a diagnosis of any kind is confronting the unknown - what exactly is Parkinson's disease? Where am I today in the process of this disease? What can I expect tomorrow and the days after? This article is intended to offer broad strategies for caring for a person with Parkinson's disease as well as identifying and accessing useful resources.

Educate Yourself

PD is a complicated illness that involves both physical and emotional symptoms. The symptoms and challenges faced by a person coping with PD may vary greatly and it is often difficult to know what to expect

PD is a progressive illness which means the symptoms will change and often worsen over time. Understanding that this will occur can help prepare you for the future. It is often helpful to keep in mind that PD and its treatment create a situation of "more questions than answers." Unfortunately, not every symptom of the disease can be managed by medical treatment.

Learning about what issues are related to PD can assist both you and your loved one ask important questions and make educated choices during healthcare visits. A better understanding of Parkinson's by everyone concerned will result in more effective coping, proper long-term management, and a more successful therapeutic outcome.

Understand that PD is Unpredictable

One aspect of this disease that confuses many families is that the symptoms and their severity can vary from day to day. How is it that "Mom" can prepare meals on Monday but be unable to do so on Tuesday? The severity of PD symptoms can vary throughout the day as well. Proper medical management is the key to keeping the most predictable response to treatment. However, as the disease progresses, fluctuations in response to treatment can occur. Most people with PD are managing and performing at their personal best. Abrupt changes in a person's ability to move and complete common activities should be discussed with the healthcare provider.

Managing the Disease

As a caregiver for a person with Parkinson's disease you have significant responsibility. This may include building a relationship with the neurologist and healthcare team; coordinating needed treatment interventions; obtaining any needed adaptive equipment or clothing; and optimizing the overall health for the person with PD through medication, exercise, nutrition and socialization. You are your loved one's advocate and thus you will dedicate much time to this effort. You will probably find that documenting office visits and changes to treatment, maintaining detailed calendars or diaries, the use of pillboxes and other assistive devices will help lessen the stress involved with these tasks.

Acknowledge Your Feelings

As a caregiver you will face challenging experiences. Recognize that emotional responses are natural but can sometimes feel uncomfortable. Avoid acting on emotions with unconstructive behaviors. The best way to do this is to express these feelings in some way. Many people find that just talking about their feelings will help. The key is finding someone who will listen without judging your emotions. When there is no one to listen, simply writing down how you feel may be your best option.

Develop Coping Strategies

It is often difficult to maintain or develop new relationships, recreational activities, or hobbies. However, it is important for you as a caregiver to do this. Consider joining a support group. Support groups can help because people attending understand and can empathize, often advise and just be a listening ear when you need it most. Members know how it truly feels to live with PD and be a source of comfort. Counseling is also helpful when friendly support is not enough. Social workers and psychologists are trained to assist caregivers dealing with chronic disease. You will need support for yourself - find it.

Keep Your Own Needs in Mind

PD can be an isolating illness. For some the symptoms can create embarrassment and difficulty navigating crowded environments. Many couples refrain from social activities such as eating out with friends. As a caregiver it will be important for you to continue with your personal social life. Meeting a friend for a favorite activity such as bridge or lunch will not only keep you connected to a support network but also give you time away from your caregiver role. This is your "therapy." Consider it a written prescription at every visit to the doctor (even ask to have one written just so you are more apt to fill it!). Do not neglect your own health. Caregivers tend to put their own needs on the back burner. You cannot care for someone else if you are not caring for yourself first.

Ask for and Accept Help

This is one of the most difficult things for caregivers to do. You have to recognize that you cannot do it alone; you will need assistance. This help may be from other family members, friends or even agencies. You need a break from your care giving demands and accepting this is necessary in order for you to get through the disease process. If someone offers to help, be specific about what he/she can do. Any small task that can be assigned to someone else will ease the demands on you.. Most of your friends and family are just waiting to help but, first you have to tell them what you need. Asking for assistance is a positive step for you.

Preparing for the Future

Because PD affects people at different ages and stages of life, preparing for the future is dependent on what has been done previously. Young onset PD presents unique challenges. Some of these challenges are financial. Loss of a job earlier than expected because of a chronic illness often requires applying for Social Security disability. Obtaining approval can be a lengthy process and should be approached in a careful manner. The American Parkinson Disease Association National Young Onset Center is a wonderful resource to support and guide you..

Medicare itself does not fully address the needs of those affected by a chronic illness. Companion or custodial care is not covered under the current provisions. Having someone help in the home must be paid for with your own funds. Therefore, it is essential that couples and families have frank and open discussions about financial matters. Elder care attorneys and financial planners are often a good investment in becoming prepared for the future.

Making Tough Choices

None of us want to make difficult decisions especially when it involves someone we love. First and foremost you must discuss issues that you might face with your loved one. Keep in mind that their wishes might not always agree with yours; however, open and honest communication is crucial for you to make these difficult decisions. We are not our best thinkers in times of crisis; be ready to have a plan in place even through it may be difficult to carry out. Issues to consider are alternative living arrangements, living wills, durable power of attorney and medical interventions that prolong life.

Conclusion

Being a caregiver is not easy. Know that you are the most important person that cares for the person with PD and keep both this person and yourself in the highest regard.

The American Parkinson Disease Association is here to help. They provide many resources to assist caregivers. There are 62 Information and Referral Centers, throughout the United States, staffed by coordinators who provide guidance and support for you and the person for whom you care for. The coordinators work closely with a network of Support Groups. They provide information on the best literature and websites available for caregivers. In addition, coordinators refer caregivers to many supportive individuals and agencies. These include but are not limited to:

Area Agencies on Aging
Support Groups for Individuals and Families affected by Parkinson's disease
Caregiver Support Groups
Grief Support Groups
APDA National Young Onset Center
Places of Worship
Home Health Care Agencies
Respite Service/Day Program Agencies
VAMC Programs for Veterans
Elder Care Attorneys
Financial Planners

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