



THE AMERICAN PARKINSON DISEASE ASSOCIATION, INC.

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EDUCATIONAL SUPPLEMENT #8

The Family Unit And Parkinson's Disease

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Introduction

Parkinson's disease (PD) is an unwanted intruder and a potentially strong and disruptive force which can upset the emotional and economic relationship in the family. Recognizing that PD has an impact far greater than on the individual alone can help marshal the needed resources to ease the burden for the individual and family alike and foster a sense of cooperation and adaptive behavior.

Function of the Family

The word family brings forth a special

image and feelings about self and relationships to others who are closely bonded with shared experiences. When functioning well, the family promotes the welfare and wellbeing of its members. When an illness such as PD strikes, these family relationships may become stressed. How the individual and family weather the storm depends on how healthy the relationships were prior to the onset of the disease. The outcome depends on the severity of the disease, the personalities of the affected individual and other family members, the degree of interdependence and integration of the family, the cultural background and

the ability to adapt and adjust to new circumstances.

Reaction of the Patient to Illness

Each individual has a unique personality and coping style and will react to illness differently. Normal emotional feelings occur in response to illness and include anger, guilt, resentment and minor depression. Adaptive behavior includes acceptance of the situation and appropriate attempts to regain control of an overwhelming situation individually or by seeking outside support.

Maladaptive behavior can emerge and includes denial of the situation, major depression and withdrawal and inappropriate overcompensation. The amount and quality of socialization with others may also be severely affected.

When early symptoms of PD begin to emerge, they may be misinterpreted or attributed to aging and depression. The lack of motivation, decreased desire for activity or decreased ability to concentrate may be noted first at work by a supervisor or at home by a spouse. When confronted with a concern about a decline in performance or productivity, the patient may become defensive or exhibit denial. Some individuals always need to be in control and will look at any attempt to question their ability or to help them as an attempt to control them or, at the very least, an unpleasant reminder that something is wrong with them. Rather than being grateful, the patient appears hostile and upset.

Alternatively, some patients become more dependent on others and will accept any and all help gratefully to the point of becoming increasingly more dependent and eventually helpless. Understanding the basic personality of the individual permits a better selection of the appropriate approach

to that person.

Reaction of the Spouse (Caregiver)

Just as the patient has a unique personality, so does the spouse. The major coping style of the spouse will color the reaction to the illness. At an early stage of illness, before PD is recognized, the spouse may respond by becoming overprotective and may overwork to the point of exhaustion. On the other hand, the spouse may feel overwhelmed and try to avoid the situation as much as possible. Generally, because PD strikes older people more frequently, the spouses have bonded together for a sufficient time to remain supportive of each other. New research strongly suggests that spouses of individuals with chronic health problems often develop significant health problems of their own related to long term caregiving. As a caregiver it is important to take care of ones' self and maintain their own health.

Adjustment of Spousal Roles

The occurrence of PD may cause a power shift in the spousal relationship and require an adjustment of roles. This change may unfold smoothly or may be a source of strife, depending on pre-existing family dynamics and whether or not the disease affects a currently employed breadwinner. Most healthy marriage relationships incorporate a degree of independence coupled with a mutual sharing. Other less adaptive relationships include: a) a mirroring type in which the spouses are inseparable without outside interests apart from each other; b) a satellite type in which the family activity all revolves around a certain person like the spokes of a wheel around the hub in a somewhat authoritarian manner; c) the marriage of convenience in which the individuals coexist deriving a measure of

companionship and economic benefit without strong bonding. If the sharing model exists, understanding or mutuality can overcome the usual conflicts, which flow from change in independence to dependence, without increasing either guilt or resentment. The other models are less adaptive when the relationships are destabilized. In the satellite model, one spouse may not be able to cope with the new found authority and responsibility and is unaccustomed to making decisions, while the other has been accustomed to giving orders, but not taking them. In the mirroring type, the inability of one spouse to keep up with the other alters the relationship and forces the spouse either to give up his/her favorite pursuits or establish new relationships, which have been avoided in the past. In the marriage of convenience, the pair may simply drift farther apart.

Outside Resources

The successful resolution of the effect of PD on the family involves utilizing resources outside the nuclear family that may include the extended family, friends, church or synagogue, the physician, support groups and national organizations. In utilizing these resources an informed patient and family will be more successful in understanding the proper expectations concerning prognosis and rehabilitative efforts.

Friends play a particularly important role in the life of the Parkinson's patient. Many patients tend to lose initiative and withdraw from their circle of friends. "I can't play cards because the shaking gives away my hand." "I don't want anyone to see me this way." If the friends can get past the excuses, and "drag the patient out of the closet", both will be better for it. Obviously, judgement in

matching the activity to the patient's condition is needed to foster a sense of enjoyment, achievement and success.

The physician has a special relationship, which is more than prescribing medication. Through good rapport and honest communication, he/she can convey a realistic expectation tempered with encouragement and hope for the future. The physician can help the patient evaluate the advantages and disadvantages of available options, such as physical therapy and new pharmacological and neurosurgical advances. Again the individual styles of the physician, the patient and the family will affect the relationships. Many physicians will bring the family into the room with the patient during the examination and evaluation to facilitate communication and to insure that instructions are clearly understood. Physicians need to be prepared to answer sophisticated questions and sometimes be able to say "I don't know." All in all the physician can be a coach for the patient and family to encourage the greatest independence possible and provide a stabilizing force to help the family cope.

The family should develop a relationship with a local support group. This action permits the development of relationships outside the family including social interaction, physical conditioning and emotionally corrective experiences. Some patients do not want to know too much about PD, to see someone worse than themselves or have others see them.

Their wishes should be respected, but alternative approaches should also be explored. The support group is a tremendous source of information about the disease itself and ways of coping with it. Affiliation with a national association, such as APDA, provides yet other resources.

APDA is focused on finding the cure by funding research projects and the Information and Referral Centers to support the patients and caregivers through education. For the listing of a center in your area, you can call the APDA national office. APDA has two special Centers – one dedicated to support armed forces veterans, (Tel. No. 775-328-1715) and one to support Young-Onset Parkinsonians, (Tel. No. 877-223-3801).

Furthermore, through the Internet, at www.apdaparkinson.org, APDA provides current information which is actively pursued by patients and families alike.

Conclusion

Even though PD can affect the family unit negatively, a well planned, active approach with good communication and cooperation of everyone involved will foster a spirit of hope and ease the burden for those who walk this path.

The information contained in this supplement is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's own physician.



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