

We Are There

A Guide By Caregivers
for Caregivers of
Parkinson's Disease Patients

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MISSION STATEMENT

National Parkinson Foundation Orange County Chapter

To serve the Parkinson community of Orange County through education, awareness, care, and support of research.

To provide resources through fund-raising endeavors that will contribute to the research effort to find a cure for Parkinson's disease.

Preface:

It has been said that the only constant is change. That statement is particularly true for Parkinson's disease patients. Frequent adjustments will be required of both the patient and the caregiver, resulting in gradual transitions in the roles each will play in the daily struggle with this slowly progressive disease.

With this in mind, "We Are There" has been written to help other caregivers as they walk the route traveled by those who contributed to this brochure. It has been developed with three primary goals:

1. To eliminate the feeling of isolation. Many caregivers feel they are alone. You are not. As you will see, the path is a difficult but well-traveled one.
2. To serve as a resource for substitute caregivers. When the primary person must be away for a short time or an extended period, this brochure will provide a "quick read" for an alternate. In addition to general concepts, charts to enter individual information are provided on pages 39 – 41.
3. To help both caregiver and patient anticipate what might lie ahead. The inevitable changes will usually result in a constantly expanding role for the caregiver. If both parties know what may occur, careful long-range planning can make the adjustments easier for each of them.



Who Are Caregivers?

Most often caregivers are family members – a spouse, child, or other relative who must assume responsibility for a person who can no longer independently perform all of life's daily activities. Many individuals find that the normal aging process makes it difficult for them to do everything they once could easily accomplish. But when they are impacted by an illness such as Parkinson's disease, the challenge can become insurmountable without regular support from another person.

Parkinson's is an extremely individualized disease, affecting patients in various ways and at different rates. As a result the ability of patients to perform specific tasks will not only vary from person to person, but may fluctuate for any given individual from day to day. The times when a patient is least affected, and therefore able to successfully complete more activities, are described as "on" times; conversely, "off" times refer to instances when Parkinson's disease is having a greater impact on the patient's ability to function.

For many Parkinson's patients, there will be a gradual decline in independence over time. This will affect not only the patient but the caregiver as well. What may have started as an occasional need might advance to the point that being the support for another could become a full-time job.

Caregivers and patients are "in it together," and the changes that will occur over a prolonged period have physical consequences for both parties, as well as emotional ones. Is it a negative change, a loss of independence? Perhaps. But wouldn't it be better to take advantage of this opportunity to create an interdependent partnership based on the revised roles?

Establishing a Partnership:

The most fundamental requirement in any relationship is good communication, and that certainly is true in the patient-caregiver partnership. Relying on assumptions rather than open dialogue is likely to generate frustration and role conflicts. Both patient and caregiver must be certain that their expectations and needs have been clearly understood by the other party.

The best way to be sure that understanding has taken place is through questions and answers. Yesterday's needs will not necessarily be the same ones that are paramount today. The individual nature of the disease means that all but the most routine tasks should be re-examined daily. The caregiver must ask. The patient must explain to the best of his/her ability. If either one is hesitant in expressing feelings, it is more important, not less, that the other fill that communication gap. And both, on a daily basis, must strive to be certain that the patient's needs are clearly identified and met. It is equally important for the caregiver to make certain that the patient understands why certain activities are taking place and the specific benefits that will occur as a result. Schedules should be established, preferences understood, and routines implemented. Such patterns will benefit both the patient and the caregiver.

An initial diagnosis of Parkinson's disease is likely to be very traumatic to a patient. Some people may go into denial. Others may rely on previously acquired misconceptions, and assume their situation is hopeless. Nothing could be further from the truth. For as long as possible, in as many ways as possible, the patient should carry out all the roles that he or she is capable of implementing. This is necessary for the individual who wants to maintain a sense of independence. It is also important for the caregiver who will increasingly face a loss of personal and leisure time. Both patient and caregiver may feel a loss of freedom and an increasing sense of isolation. On the other hand, with a genuine effort, closer relationships may be formed between the partners as they strive to strengthen their rapport while constantly adjusting their roles.

Areas of Support:

Most Parkinson's patients will not require a caregiver's support when they are initially diagnosed. However, as the disease progresses, it will become increasingly difficult for many people to function independently. If there is one general statement that can be made, it is that actions that once were automatic no longer will be; they must become practiced, conscious functions. Despite the fact that more time will be needed for just about everything, the patient should be encouraged to do as much as possible without assistance for as long as seems reasonable. It is important to maintain a sense of independence and the ability to make choices. It is, however, impossible to predict the point at which assistance may be necessary because of the differing rates at which patients are impacted.

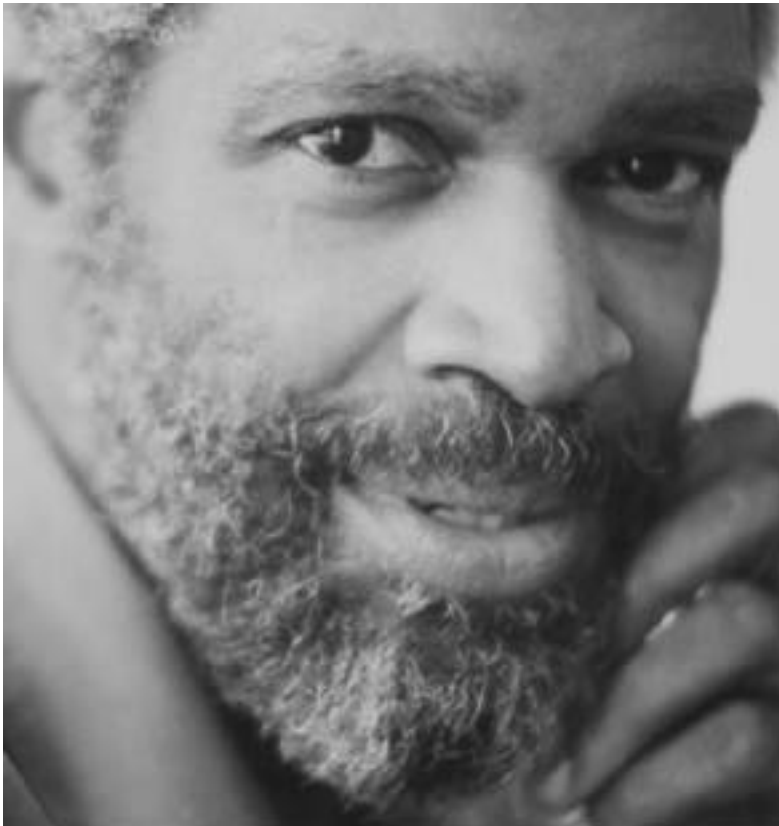
Not only is the time frame unique with each person, but so are the specific functions that may be impacted by advancing Parkinson's. Only one or two areas may be affected in some patients, while others may find that they will need assistance with a number of functions. This booklet is divided into the following areas where support may be required:

- Cooking, Eating, and Drinking
- Toilet and Bath
- Dressing and Grooming
- Medications and Health Care
- Speaking, Reading, and Writing
- Sleeping, Exercise, and Therapy
- Housekeeping
- Mobility, Travel, and Transportation
- Finances, Economics, and Insurance

Regardless of the activity, there are certain fundamental guidelines that will make every process easier and more effective for all concerned. Careful planning should precede every action – from eating to bathing to dressing; all supplies and equipment that are needed for that function should be gathered in advance and placed where they are readily available. Some functions cannot be interrupted because it is inconvenient; even more important, it can create an unsafe atmosphere for the patient if the caregiver must leave to

secure an item that was forgotten. By planning activities together, the patient and caregiver can share the responsibility and increase the likelihood that the tasks that follow will be more effectively and pleasantly completed.

On the following pages you will find specific suggestions for each of the previously identified topics. They are not all equal in significance, and all may not be necessary daily. One of the first things a patient and caregiver can do together is to establish the importance and frequency of assistance that is required.



Cooking, Eating, and Drinking:

There is no place in the house more dangerous than the kitchen. Sharp objects, boiling water, and hot surfaces like a stove burner cause injuries to people every day. If this is true for the general population, imagine how the likelihood of injury increases for a Parkinson's patient. While the advice throughout this manual is that the patient should do as much as possible for as long as possible, food preparation is one area that must be extremely carefully evaluated. If a tremor is present...if there are balance problems...if strength has been reduced in the hands, discretion should replace valor. That does not mean that the patient should be banished from an area where he or she may have played a significant role.

There are certain tasks that are not as inherently dangerous as others, and those are the tasks that can still be fulfilled by the patient. The caregiver, on the other hand, might better be the individual who drains the boiling water, cuts with a sharp knife, or places things under the broiler. Certainly each can share in the development of a grocery list and the actual planning of the meals, but there will be a point at which it makes no sense to jeopardize someone's health in the home's "accident center" just to stay active and involved.

This might be a good time to point out that this publication is not intended to replace the best professional advice. Rather, it is assumed that the patient is relying on a wide range of trained personnel to make most decisions. In the case of eating and drinking, that means that the unique needs should have been addressed by a nutritionist or dietician in order to develop a specific plan.

While the exact reason for it is not clear, many Parkinson's patients tend to lose weight. That means that supplementary sources of certain vitamins or nutrients must be implemented. On recommendation from a doctor, the nutritionist or dietician can chart a course that will best meet the patient's needs. The traditional three meals a day might better be replaced with more frequent, smaller servings. Meals should be timed with a patient's "on" periods so that they do not become unpleasant eating marathons. Perhaps fiber should be added to the diet to counteract constipation. Calcium may be recommended to strengthen bones, especially if the patient is prone to

falls and therefore possible broken bones. Supplements like Ensure may be suggested by the doctor or nutritionist. In any event, it is important to remember that food is an important part of the treatment regimen.

There are special eating utensils available that might better meet the patient's needs. Curved handles can reduce the amount of arm movement necessary to raise food to the mouth. Not only should these utensils be used at home, but they should also be carried to restaurants. Just be certain that they are brought home rather than left behind to be cleared back to the restaurant's kitchen. Even with special utensils, some foods may require extra assistance from the caregiver. One of the first things that comes to mind is the cutting of meat to bite-size portions. It is not as embarrassing as it might sound, and it certainly makes the chewing and swallowing process much easier. There is nothing that says that we have to eat certain foods with certain utensils. Wouldn't we all rather use a spoon to eat peas? While most would consider that a social gaffe, for the Parkinson's patient it only makes sense. Pasta meals can better be handled in a soup bowl. Order them that way when dining out too. Soup is easier to handle in a large cup. Soup spoons generally make more sense than dessert spoons, if you don't have specially designed utensils.

At home consider using dishtowels instead of napkins to cover more of the "drip prone" areas. In restaurants ask for extra napkins and other items, such as a straw, when ordering. Special requests are typically not a problem if they are presented "up front." Since it generally takes the Parkinson's patient more time to do just about everything, it might be wise to consider dining out at less busy times. No one will feel rushed. (The same advice could apply to other venues, such as theaters where matinees are often less crowded, as well as less expensive.) If you often visit the same restaurant, the waiters will become familiar with your special requirements, and they may automatically be met without the need to ask.

A speech therapist may be another resource person who should be included in the overall planning. Swallowing techniques should be evaluated. While Parkinson's itself is not a terminal illness, difficulty in swallowing can lead to episodes of choking and aspiration

which can be fatal. It is strongly urged that the caregiver become familiar with the Heimlich maneuver. Many community agencies offer brief classes in this life-saving technique.

Swallowing difficulties apply to drinking as well as chewing. Small sips of liquids are advisable, but it is also necessary that the Parkinson's patient drink as much as possible, probably more than he or she wants to. Dehydration can be a major issue in this illness. It can only be countered by considerable fluid intake. Again, individual recommendations should come from a doctor or nutritionist. It is also necessary to drink regularly in order to assist with bowel movements. As mentioned earlier, constipation can be a problem, and liquid intake is crucial to aid in regularity.

Many patients have difficulty swallowing pills. Here the advice of the speech therapist is invaluable. Sometimes foods such as applesauce are better than liquids. Be certain that the approach that works best can be implemented away from home as easily as at



home. You should carry individual cups of applesauce or bottles of water with you so that medications can be taken at the scheduled times. While some people find it easier to swallow pills that have been crushed, some medications, including time-release formulas, are not intended to be crushed. Check with the pharmacist before crushing any medication.

As swallowing becomes more difficult, it is usually "thin" liquids that pose the greatest problem. Nectar is a smooth fruit drink that slides down the throat easily, minimizing the constant danger of choking. There are products available in pharmacies that thicken liquids; by stirring in such tasteless supplements, "thin" liquids can be more readily accommodated by the Parkinson's patient. For some, a straw is not practical because the sucking ability is restricted. For others, straws are a big help. When using a smaller glass, though, it might be advisable to cut the excess portion of the straw so that only an inch or two extends beyond the rim.

Good dental care is an important component of a comprehensive medical plan. Regular check-ups will ensure that teeth and gums are healthy. Since many Parkinson's patients lose weight, which may lead to changes in facial contour, periodic denture adjustments may be necessary.

Eating and drinking are necessary to maintain the best possible health. They can, however, be among the greatest frustrations for both the patient and caregiver. If all professional recommendations are followed, and personal adjustments are made - probably through trial and error - the experiences should be more rewarding ones.

Toilet and Bath:

If the kitchen is the most dangerous room in the house, the bathroom is certainly second. It is absolutely essential that common sense precautions be taken that will protect the Parkinson's patient from preventable falls and other injuries. If carpeting is not a reasonable alternative because of incontinence or other difficulties, then throw rugs must be secured with rubber backing. Glass shower doors should be replaced by safety Plexiglas or a shower curtain. Paper or plastic should be substituted for drinking glasses.

Several other suggestions will be made in the following paragraphs. Many involve physical modifications to the home. Specialty stores may have some of the suggested items, or you may want to consider a trip to a medical supply store, or a search of the Internet for sources and ideas. Spend some time browsing through health care catalogs. You may be amazed at some of the health aids that you never considered, items that will fill a unique need that may or may not be addressed in this pamphlet. It will only take an hour to review the options available, and you may find products that will enable you to save more time than that daily. The eating utensils in the previous section are one example; bathroom grab bars, described below, are another one.

One of the highlights of a young child's growth cycle is success at potty training. From that point on we seldom think too much about this seemingly automatic function until the unthinkable happens. Incontinence. It is certainly one of the most embarrassing aspects of Parkinson's disease. The decrease in control can be helped, at least temporarily, by medications. Another specialist, the urologist, may be visited frequently with varying degrees of success. The patient may try an approach such as timed voiding where the bathroom is visited at regular intervals rather than in response to an urge. Slowness of movement, difficulty with clothing, and lack of muscle control may all lead to incidents of incontinence.

Ultimately there may not be a solution, just an alternative. There are a number of different commercial products available in groceries, pharmacies, and discount stores. Whether pads or protective undergarments, the insulating items allow both men and women to

lead an anxiety-free normal life. Most people wear them not only during the day but at night as well. Extra protection should always be carried in the trunk of the car, packed as part of vacation travel, and included in a purse or backpack when on short daily trips. In addition, a waterproof mattress pad will provide additional protection during the night.

Incontinence is not the only bathroom-related problem. For many Parkinson's patients constipation is even a greater problem. It can result from diet, medications, or nerve degeneration. Regardless of the cause, it is a major health issue that must be addressed. A doctor may prescribe a stool softener. A nutritionist may adjust the amount of fiber in the diet or recommend supplements. But no one can provide assistance if the medical team is not aware that the patient has a problem. Sometimes people are embarrassed to talk about constipation. It is essential that such feelings be overcome so relief can be brought for this problem.

Thus far we have focused on problems "within" the patient. It is also necessary to consider problems within the bathroom facilities. It will may be necessary to make structural changes to the home. Nowhere is this more likely to take place than in the bathroom. With changes, it may be possible for the patient to use the bathroom without assistance. Certainly that would be emotionally preferable. Whether that is the case or not, it would seem advisable for the patient and caregiver to plan together to determine which changes in the physical structure will best address the needs of the patient. Again, the catalog at a medical supply store should be required reading for both parties.

Why do we need structural changes? There may be many reasons, but foremost among them are matters of balance, turning, and the inability to rise from a seated position. Some of the options that should be considered are securely mounted grab bars by the toilet, a frame with armrests that stands over the toilet seat, or a raised toilet seat. Since patients often have limited strength or flexibility in their hands, personal cleanliness can be a significant issue. It is possible to retrofit a standard toilet so that it functions as a bidet. The pressing of a button can relieve physical struggling and ease anxiety that would otherwise be present.



Structural adjustments may also be necessary when it comes to bathing. In fact, bathing may not be the right term, for most Parkinson's patients cannot get down into or up from a slippery bathtub. Showering is certainly the preferable alternative, but even that can be dangerous. Non-slip strips on the floor are truly essential, as are secure grab bars. Towel racks are not intended to hold a person's weight; they will pull

out from the wall and are not satisfactory replacements for properly installed grab bars. A shower seat is another advisable addition. Water temperature should be adjusted before the person steps into the shower. A hand-held showerhead on a flexible hose will increase the ability of a seated person to clean him/herself. If an individual drops a bar of soap, the resulting struggle to pick it up can lead to balance problems and a subsequent fall that could cause broken bones or worse. Use a plastic bottle with liquid body soap or shower gel that can be placed on a shelf next to the patient. There may be other needs such as sponges, shampoo, or other cleansing items. To repeat an earlier point – be certain that everything is gathered in advance and placed in convenient locations so that the patient need never be left alone in a potentially dangerous situation.

Despite all of those adjustments and precautions, at some point it may not be safe to allow the patient in the shower alone. Showering together, however, is not the answer by itself. A slippery body can be very difficult to hold upright. Grab bars are still essential, as are protective strips on the shower floor. It is possible to easily change a single showerhead to a double head if that is desirable. It might well enable the caregiver to simultaneously get clean, eliminating the need to later leave the patient alone. Since the patient may have his/her eyes closed because of the water spray, always explain what

you are going to do in order to avoid startling him or her. This is especially true when shampooing the individual's hair since a series of steps (shampoo, rinse, conditioner, rinse) may be involved. Be certain that the patient is safe – either seated or holding a grab bar – before completing other tasks such as returning the shampoo to its place or turning off the water. Again, explain to the patient what steps are being taken prior to assisting him/her from the shower. A large terry cloth robe may be preferable to a towel for initial drying, but careful attention will ultimately have to be paid to those body areas that might chafe if not properly dried.

Showering and toilet use are among the most basic of needs that a caregiver will have to assist a Parkinson's patient to meet. But emotionally the feeling of cleanliness cannot have too high a value ascribed to it. The use of the shower should be scheduled to take place at a time when the patient is generally "on." There are two other requirements that must be followed rigorously. The patient must NEVER lock the bathroom door when in that facility alone; it might even be necessary to alter the mechanism to avoid its locking accidentally. Whether or not the patient is able to independently move from the bed to the bathroom at night, a night light must ALWAYS be on to assist that journey for the individual alone or with the caregiver.



Dressing and Grooming:

If the Parkinson patient is no longer working, the choice of clothing will certainly be more casual than that required for the workplace. Again, the extent of the illness will determine whether assistance is needed throughout the dressing process or only to lay out the patient's clothes. Regardless of who does the dressing, clothes should be arranged in sequential order. It is also important that the patient remain fully involved in selection of the day's outfit.

An illness like Parkinson's will necessitate a change in wardrobe. Velcro and elastic may have to replace buttons and zippers. Loose, lightweight garments that close in front will make dressing much easier. Elastic shoelaces and slip-on shoes will ease the task of tying laces. In selecting footwear, leather shoes are much less likely to lead to tripping than rubber or crepe that may get "caught" on carpets. Tube socks are preferable to dress socks. One of the few positive benefits for women may be that pantyhose may be a thing of the past. If it is necessary to replenish a wardrobe, the patient should be involved in the shopping to select favorite colors and – within limitations – styles. Favorite items of clothing can be adapted by a tailor to replace buttons with Velcro.

If there are items of clothing that are no longer appropriate to the patient's condition, they should be stored away or moved to the back of the closet. Getting rid of them may be emotionally discouraging and dull the hope of the patient. When those items that are going to be worn regularly are moved to a more prominent position, it will make it easier for the patient to select a day's outfit, and for either patient or caregiver to arrange that clothing. In the actual dressing process, whether assisted or not, clothes should initially be placed on the patient's stiffer side. It will be easier if the patient's more flexible side is dressed after the affected side.

Personal grooming is another area that may be completed by the patient, or it may be necessary for the caregiver to provide assistance. An electric razor can make the shaving process easier and safer for both men and women. Similarly, electric toothbrushes may ease the cleaning of teeth or even dentures. If either of these activities is to be completed in the old-fashioned way, be certain that all

supplies are gathered in advance so the patient need not be unattended during an interruption in the activity.

If the patient is unable to complete tasks involving nail and/or hair care, this would be an opportunity to avail oneself of a manicurist or cosmetician. Several advantages would be realized. The results would be relatively superior. While the patient is involved in a pleasurable activity, the caregiver would gain a respite to tend to personal needs. Furthermore, it would provide a socializing opportunity for the patient, particularly if regular, periodic appointments were held at the same location. Parkinson's disease might necessitate a change to a more easily manageable hairstyle. This should be presented as a positive venture where the patient and a stylist can jointly select a flattering style that will also be relatively easy for the patient to care for. If the caregiver is going to be responsible for daily care, he or she might wish to be present with the stylist when suggestions are initially made for maintaining the patient's appearance.

If one looks one's best, it is likely that an emotional lift may be received. Personal care, particularly for women with cosmetics and hairstyle, may require an excessive amount of time, but the feeling of self-accomplishment could be immeasurable. If these tasks are beyond the ability of the patient, then the caregiver's attention might still provide the desired "boost."



Medications and Health Care:

Regrettably, for many Parkinson's patients this is what it is all about. The daily routine is dominated by sequences of pills taken at prescribed times. Sometimes the routine may be annoying and inconvenient, but without medications the ability to lead a "normal" life would be difficult, if not impossible. Parkinson's is a chronic illness. It is not something that the patient will recover from. Rather than looking forward to a recovery, the patient, caregiver, and family must alter their future expectations to accommodate the impacts of this lifelong illness.

Because Parkinson's is so uniquely individual, those adjustments may be minimal or truly significant, based on the stage of the illness, the rate of progress, and the overall health of the patient. Medications that work for one person may not be at all effective for another. Even more confusing is the fact that dosages which may have been truly beneficial for an individual one day may seem to have lost their effectiveness on another day. Comprehensive records must be maintained so that data can be shared with doctors who may respond by adjusting the dosage, frequency, or even the medicine itself. A blank form to keep track of personal information is provided in the "Records" section on page 39.

Since the average age of onset is 55, it is not unlikely that the Parkinson's patient may also be experiencing other medical problems. More than one doctor may be seen regularly. If that is the case, copies of each doctor's file and prescribed medications should be forwarded to the primary care physician. The neurologist may be focusing on Parkinson's related issues, while a second doctor might be treating diabetes, and the primary physician may be monitoring blood clots near the heart. It is imperative that each is aware of the overall medical picture.

Combinations of medications may have adverse reactions with one another; therefore EACH doctor that the patient is seeing should be aware of EVERY medication that has been prescribed. For the same reason, it is strongly urged that all medications be secured from a single pharmacy where modern computer systems will often "flag" a potential problem among various drugs. It is not just prescription

drugs that can be the culprits, though. Some over-the-counter products and herbal remedies should not be taken in combination with prescription medications. A patient's entire pharmacology history should be brought to every doctor's visit, and presented in writing to the doctor at the time of the examination or consultation. If the patient has a computer available, it is a relatively easy task to track medications and reactions on a spreadsheet. In addition to drug interactions, many people have allergies; those reactions should be familiar to each doctor involved in treating the patient. Furthermore, many medications may have side effects. Always ask what potential difficulties may occur from taking specific drugs.

Frequently doctors or laboratories may administer tests. Those results should be available to the patient so they can be shared with other physicians who may also be providing treatments. Always request a copy of the results, read them over, and ask questions if you need clarification; then personally make certain that information gets in the hands of other doctors. A change in the patient's status, determined by one physician, may be crucial to the treatment provided by another doctor.

Although it is important that the patient maintain as much independence as possible, it is also imperative that the caregiver be present at every doctor's appointment. This is not contradictory in nature. Sometimes people focus on one portion of a conversation and miss the subsequent facts as they are still mentally "digesting" the original portion of the message. A notebook may help to record crucial data, and two sets of ears make it less likely that confusion will occur. If the patient should undergo an adverse reaction to a specific drug, it is important that the caregiver be aware that possibility existed. Hallucinations, for example, might be much better dealt with if the caregiver is aware that certain medications might cause those reactions. Both the patient and caregiver should share a detailed analysis of the diagnosis, alternative treatments, and referrals to other specialists. Both should be aware why those referrals have been made and what the potential results of different treatments might mean to the patient's daily life.

At the outset of this publication, the patient-caregiver relationship was described as an interdependent partnership. Nowhere is that

relationship more important than when both are in the doctor's office. The ability to share information afterwards is enhanced multifold over the casual "What did the doctor say?" conversation that might occur if the caregiver were not present to personally interact with the doctor. Nor is the caregiver there just to listen. While questions will be primarily addressed from the doctor to the patient, at times the more accurate responses may subsequently have to come from the caregiver should the patient be confused or suffer from memory lapses. Communication with any health professional is a two-way street; the patient (or caregiver) must acknowledge to the doctor the existence of depression, anxiety, eating disorders, or incontinence – just to name a few concerns – in order for the professional to respond and offer appropriate treatment.

When it comes to medications, simply having the right pills that will not adversely interact with one another is not enough. The patient must take the pills at the prescribed time. As simple as that last statement sounds, it is not! A number of problems may occur in the medication process. As was mentioned in an earlier section, some patients have difficulty in swallowing water without choking or aspirating. If a substitute such as applesauce is involved, it must be available when it is time to take medications. Similarly, water is not automatically present at all times. A bottle of water or juice should be carried even when the patient expects to be home in time to take his/her pills. Schedules often go awry, but inconveniences or delays should not be allowed to impact the medication schedule. A small supply of pills should always be carried when away from home. If a lengthy trip is taking place, pills should NEVER be packed in luggage. We are all familiar with horror stories about lost luggage. A missing pair of shoes is annoying; missing medications may be crucial to an individual's health.

Being in possession of one's medications does not necessarily mean that they will be taken as scheduled. People can become distracted or simply forget. A device such as a kitchen timer or a watch with an alarm is advisable. It should be set for the next interval at the time when the immediate pills are taken. Which pills? When a patient is taking a wide series of medications, it is possible to get confused over the specific ones that should be taken at 1 PM. A written record is absolutely essential. (See "Records" section on page

39.) It might also be wise to secure a small pillbox with specific pills located in individual slots. This could be "loaded" each morning. If possible, the patient and caregiver should do this together, reaffirming that each knows what medications are taken at various times, and what the purpose of each is. Despite the best efforts of both parties, occasionally an interval might be missed. Do not double up on pills unless authorized by your doctor; instead, within reasonable parameters, adjust the times of subsequent pills. Establishing a systematic procedure will also ensure that inadvertent overdosing does not occur. If an individual is confused or uncertain whether the 1 PM pills were taken, the empty slot in a compartmentalized box will confirm that they were indeed taken, thus avoiding a potential overdose with its negative consequences.

A regular process should also be established for refilling prescriptions. Do not wait until the last minute. Two or three days before you will run out, place a refill order and then schedule your own time to pick up that prescription so that the process can continue in an uninterrupted manner. If childproof caps are a problem, be sure to indicate that to the pharmacy clerk.

While daily life will hopefully emphasize wellness rather than illness, one of the best ways to be certain that each day's activities are maximized is through periodic doctor's appointments and adherence to a strict regimen of medications. The World Health Organization uses the distinctions of *impairment*, *disability*, and *handicap* to describe a disease's consequences. *Impairment* refers to a disease's physical symptoms; in Parkinson's disease that generally refers to a body's motor functions. *Disability* is the effect that the impairment has on a person's behavior and daily activities. *Handicap* is a much more general term, referring to the effect the illness has on the personal and social aspects of life. Not all impairments result in disability, and not all disabilities can be considered as handicapping. It is, after all, a unique, personal illness.

Speaking, Reading, and Writing:

Communication is the key to interpersonal success for most people. While there are alternative means to interact – using a gesture or expression, for example – for most communication the ability to speak, read, and write is crucial. Unfortunately, as with virtually every motor function, these interactive skills can also be impacted by Parkinson's disease. Early intervention to counter limitations that may occur, particularly in speaking, will make the process much easier than attempting to recover skills that have been severely impacted.

As Parkinson's disease progresses, many patients have difficulty swallowing because saliva collects in their mouths, resulting in drooling. In addition to that, it becomes difficult to project the voice. Both the speaker and listeners, often the caregiver, can be frustrated by this limitation in expression. Boxes of tissues throughout the house and in the car can address the issue of saliva flow, and speech therapy will help with voice volume and a tightening of the muscles in and around the mouth and throat. It is estimated that nearly 75% of Parkinson's patients experience a change in voice or speech due to a reduction in muscle control. A speech therapist was earlier identified as an integral part of the treatment team because swallowing difficulties might ultimately be life-threatening. Individual



analysis and treatment by a therapist can also help the communications process. Activities such as singing or reading aloud are designed to increase volume.

Frequent practice with commonly used, individualized phrases that are identified by the patient or caregiver may be helpful. Many Parkinson's patients "lose steam" at the end of a sentence. While a listener should not finish the patient's thoughts for him/her, it may be advisable to repeat the portion of the sentence that was comprehended. In this way the patient will only have to repeat a portion of the thought, increasing the probability that the remainder of the sentence will be heard. There is, however, no ready solution to the word-finding difficulty that sometimes impedes a patient's conversational ability. If a synonym can readily be identified, that might enhance the dialogue.

Three suggestions might increase the patient's ability to successfully use the telephone. Large button phones may make it easier to punch in numbers, and the use of the memory/speed-dialing function can simplify the process even further. In addition, phone amplification devices can help to improve the volume when speaking. In some areas of the country local agencies may supply resources to assist disabled persons to secure such modified equipment.

One might think that reading would be an area not impacted by

Parkinson's disease. For many patients this is true, but it is not the case for all. Among the muscles that might be affected are those surrounding the eyes. Forced eyelid closure can be treated with some medications or – in more severe cases – with injections around the eyes. If this condition exists, the pleasure of reading may be lost. For these patients, as well as others, books on tape may be a positive alternative. Several libraries have them available to borrow, and some even loan tape players. For the individual whose tremors may make it difficult to hold a book steadily enough to read, portable book holders may be the solution. Some people enjoy being read to, which might enhance the patient-caregiver relationship. This is also an activity that others could participate in when the caregiver takes that much-needed break.

For the vast majority of Parkinson's patients, the ability to write legibly is something that can no longer be taken for granted. In fact, for many, one of the first symptoms is a reduction in handwriting size. Micrographia can eventually lead to the inability to form discernable letters. This can be traumatic for the patient. The Braille Institute has templates to help a patient learn to control size and spacing. At some point, it might be wise to get a patient's small, scribbled signature verified by a notary public. If the patient has the manual dexterity to type, the computer can be a wonderful way to write to friends and family without struggling to form letters and words. The use of e-mail also makes it possible to continue to correspond without some of the more formal rules that often exist in other forms of correspondence. With advances in voice-activated programs, it is even possible to create correspondence with almost no typing skills.

Social interaction is a crucial component of an individual's emotional well-being. This is an area that has been addressed more fully in a separate NPF OCC publication, "Dear Friends and Family," and interested persons are urged to secure a copy from the address on the back of this brochure. While adjustments in speaking, reading, and writing may have to be made because of Parkinson's, this is truly an area where the optimistic philosophy "where there's a will, there's a way" may well be the best approach for patient and caregiver as they develop alternatives to better meet the patient's needs and limitations.



Sleeping, Exercise, and Therapy:

It is much easier to accomplish things during the times of the day when an individual feels good. Since Parkinson's patients start with motor problems that make ordinary tasks difficult, extra steps should be taken to get proper rest, and participation is urged in both exercise and physical therapy programs.

While regular sleep is occasionally difficult for some people, that problem increases for those with Parkinson's. Changes in sleep patterns may result from a number of different reasons ranging from physical discomfort to urinary problems. Among the steps the patient can take are limiting fluids after dinner, and similarly limiting caffeine intake. Some people think alcohol will help them sleep. While that may initially be true, it is equally likely that rebound insomnia may occur with periods of wakefulness following an initial sleep cycle. Ironically insomnia may also result from the side effects of Parkinson's medications.

If it is a significant enough problem, patients should see their doctor and may wish to consider taking a sleep aid. This step, though, should only be taken after consultation with a physician and an analysis of possible interactions with other drugs the patient is taking. Bedtimes might best be varied based on whether it is an "on" or "off" day for the patient. Tiredness, rather than a preset time, is a better determinant of when to go to bed. Regardless of bedtime, an established routine can help develop patterns conducive to falling asleep. Always be certain that a night light is on in the event that it may be necessary to use the bathroom. Never attempt to walk in the dark. It is an invitation to disaster.

Regular exercise is one of the most valuable activities a Parkinson's patient can participate in. Whether it is yoga or tai chi, an organized session or individual workout, exercise can not only benefit muscles but also reduce tension and make it easier to rest. Even mental issues such as depression can be alleviated through periodic exercise. Walking and swimming are valuable activities because they help the patient to maintain a fuller range of motion while providing the benefits of periodic exercise. These are activities that the caregiver can readily share with the patient. If swimming is



involved, appropriate precautions must be taken to ensure the patient's safety. If there is a concern that the patient may overly exert while walking, the caregiver can push an empty wheel chair on the outward trip so that it is available, if necessary, on the way back home. When possible, walking should be in conjunction with another pleasurable activity, such as bird watching, rather than merely taking repetitious circles around a track. In inclement weather, walking in a mall may well be an alternative.

When selecting an activity, patients will hopefully find a passion that will keep them physically active and mentally involved as well. Dwelling on Parkinson's disease nonstop is not a healthy approach. Don't be afraid to continue activities that were enjoyed before the diagnosis. It is not necessary to be the best in an aerobics class, or to maintain the distance of your drive on the golf course. But continuing enjoyable activities will benefit the patient's emotional health while helping to keep the body limber.

It is important to begin a reasonably aggressive exercise program as soon as possible after the diagnosis of Parkinson's disease is made. Ask your doctor for a referral to a physical therapist who specializes in Parkinson's disease. The initial consultation will undoubtedly involve an evaluation of the patient's capabilities and limitations. Physical therapy will serve a dual purpose: to prevent atrophy of muscles while simultaneously assisting the patient to recover functions that have already been lost. After analysis, the therapist may prescribe activities that include exercises while standing, sitting, lying, or rising from a seated or prone position. Efforts are usually made to select activities that the individual finds pleasurable. Based on the limitations that are present, these may range from gardening or golf to arts and crafts. With a bit of luck, the choice may be something both patient and caregiver enjoy so they can interact in a more casual setting. If that is not the case, this might well be the perfect opportunity for a substitute caregiver to become involved, providing a change of pace for both patient and caregiver.

Whatever activities are undertaken, it should be remembered that the Parkinson's patient will often need additional time to prepare for and/or complete them. Failure to provide that time will create stress that will be counterproductive to any benefits that might accrue from the intended activity. Rushing to complete a task may not only be frustrating to the patient but might also be hazardous, depending on the particular activity involved.

Rest and exercise might seem like opposing concepts, but they are really parts of a continuum, and Parkinson's patients must participate in both. The trick is to strike the perfect balance between these two vital activities.

Housekeeping:

Whatever the task, it is more likely to be successfully completed if complex actions are broken into a series of simple steps. This is true of every activity, but it is especially true of housekeeping that requires more strenuous physical exertion than many other tasks.

It has already been established that most Parkinson's patients have "on" and "off" times. Since few household tasks except cooking have to be completed at specific times, it makes the most sense to tackle chores when the patient's responses are at the optimal. Even then, there are safety factors that must be considered. The strain of attempting to lift wet clothes from a washer may set the patient back for an entire day. That hardly makes sense. Alternatives should be explored. If finances permit, hiring a maid or housekeeper on a full or part-time basis might solve many problems. If it is a man who is assuming the role of caregiver, he may suddenly find himself involved in a number of equally unfamiliar roles from cooking to cleaning. Mutual planning may have to replace the former division of chores. Some can be shared; others may fall to the caregiver or another party.

While most household chores take place within the home, at least one requires travel – or it used to. Even grocery shopping can now be completed via delivery services if the person prefers that option. There are other reasons, though, that might make traditional shopping a preferable alternative. It is an opportunity to leave the home, preferably at off-peak hours for the store, where socialization may take place with friends or acquaintances. There are a number of aids that can be employed to make the task easier. Most Parkinson's patients will qualify for handicapped parking permits, enabling them to park closer to the facility. Many stores and/or shopping malls provide wheelchairs. Drive-up facilities are increasingly available for services in addition to the traditional fast food restaurants. If, however, this does not work, patients and caregivers may wish to consider catalog or Internet shopping for other than grocery purchases.

Household tasks can be onerous, or they can provide a change in routine. In any event they are relatively insignificant in comparison to the other issues in a Parkinson's patient's life. They must be kept in

the proper perspective; they are only tasks that are incidental to living. If they serve a therapeutic purpose, there is a valid reason for the patient's active involvement; if they contribute to declining health through unnecessary exertion, then alternatives should be sought.



Mobility, Travel, and Transportation:

The disparity among individuals might be at its greatest in the area of mobility. Some Parkinson's patients are still leading adventure-some lives including rewarding travel experiences. Others may be struggling to get from the side of the bed into the bathroom, and they spend much of their time confined to their home. In trying to offer suggestions for the patient-caregiver team, both realities are addressed in this section.

In moving about the home, one of the simplest rules is that traffic areas must always be kept clear. If there are children or pets in the home, their toys and other items must be placed in areas where the patient will not normally walk. Furnishings may have to be relocated if the patient has difficulty walking, especially if balance is impacted. Glass top tables should be moved to less frequently traveled areas. Other common sense precautions should be discussed so the patient has input before the caregiver makes the actual adjustments. It may be advisable to make structural changes in the home. Where possible, railings should be included on both sides of stairways. It may be necessary to add a mobile stair system or a ramp. This can involve considerable expenditure, but there may not be a choice other than relocating, depending on the severity of the handicap and the physical layout of the home. In some cases health insurance policies may provide assistance, or tax deductions may be possible. All such options should be fully explored.

For a person with balance problems, nothing can tip that balance more quickly than the routine task of carrying something. A paperback book or small plant may be very light, but it might be the thing that causes a loss of equilibrium. The resulting fall could well result in broken bones that will significantly intensify the caregiving routine. At home someone else should carry even the lightest of items if balance is a problem. Away from the home a backpack may be a solution or aggravate the problem, depending on the individual's balance and mobility. There are, of course, aids to getting around. It may be that a patient will start with a cane, although sometimes it can be more of an impediment than a help, actually causing falls. The progression to a walker and ultimately a wheelchair may be rapid in some cases, but may never take place in other instances.

Recommendations from your neurologist or physical therapist will undoubtedly be helpful in making the decision whether to use such aids. Again, the insurance and/or tax deduction implications should be pursued in order to minimize the financial impact, if possible. Some nonprofit organizations within the community may loan such devices to people in need of them.

Some of the most routine functions, things never thought about prior to acquiring Parkinson's, may now be major obstacles. There are exercises that can help an individual rise from a chair or get out of bed. When the patient is being taught those techniques, the caregiver should be present in order to help reinforce the activities in the home setting. Often the physical therapist will provide literature that illustrates the techniques to be employed. Both caregiver and patient can review those procedures until they can become an automatic part of the patient's routine. If these fundamental activities are still difficult for the patient, it might be advisable to consider a lift chair (the reverse of a recliner) that boosts the person to a standing position where he or she can begin walking. In any event, remember that a patient may have lowered blood pressure due to medications, and a sudden effort to rise could cause light-headedness and a subsequent fall. Be careful.

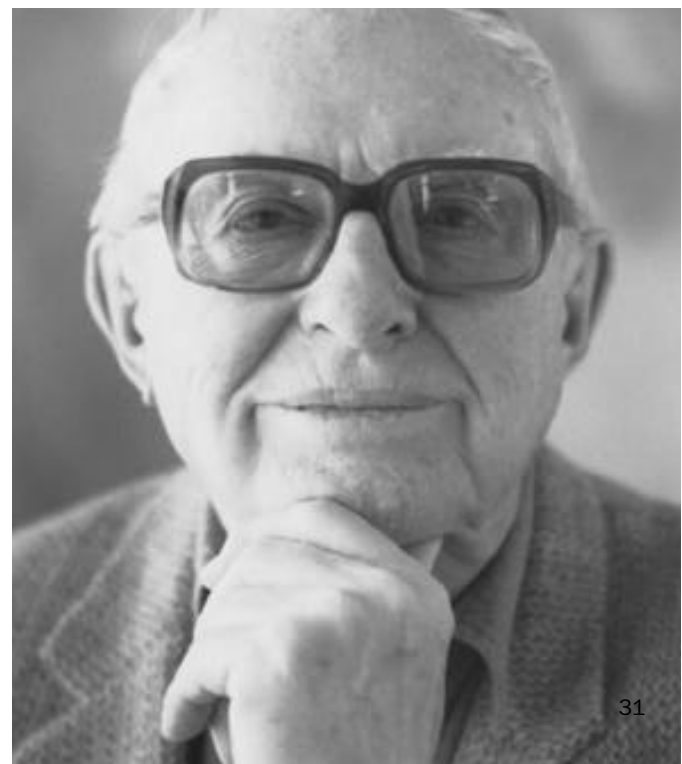
The most common means of transportation is, of course, the automobile. Many Parkinson's patients continue to drive successfully for many years after being diagnosed. For others, a decision to stop driving may have to be made. A neurological examination may lead to that conclusion. It is possible to take a road test to determine the advisability of the patient's continuing to get behind the wheel. This will not be an easy decision. There are emotional consequences to the "loss of freedom" that can be as devastating as the practical impact of no longer driving. Alternatives will have to be carefully explored. The responsibilities assumed by the caregiver will obviously increase, but this might at least partially be offset by the relief that the decision has been made.

That does not mean that the patient will now be housebound. On the contrary, it is probably now more important, not less, that the patient stay active in church or social events. Depression may set in over the inability to drive. Even if the patient would be safe at home

and is not needed on short trips to the bank or post office, getting out is good medicine. The caregiver could take the "scenic route" while completing errands, enabling both to discover a new restaurant they might want to try or to read a movie marquee and plan an evening out. Maximizing little things will help to offset the large impact of surrendering a driver's license that may have been held for fifty years or more.

On the other hand, there are individuals who are still able to travel despite the presence of Parkinson's disease. The most important piece of advice was given earlier but bears repeating. Never pack your medications; carry them in a purse or small bag that will be in your possession at all times. What would you do if you found yourself in a remote location without the drugs that provide the ability to regulate so many of your body's functions? Even if a trip is not in your immediate plans, it makes sense for the caregiver and patient to jointly develop and frequently update a checklist of items that must accompany you whenever you travel away from your home.

When making travel reservations, request a wheelchair at the airport and all connecting flights. Even if the patient doesn't normally use one, a wheelchair transports the person quickly with no tiring walk...or run, if the plane is late. A wheelchair can also accommodate two shoulder bags, and peo-





ple more readily move out of the way for wheelchairs. Ask to be boarded early. If the patient can walk on the plane unassisted, that is great, but take advantage of helping hands that are available. Special dietary needs, if any, should have been arranged at the time when the initial reservation was made, and subsequently confirmed.

While the confined area in airplane lavatories should ideally be avoided,

that may not be practical despite last minute stops before boarding the plane. In order to minimize trips up and down the aisle, seating adjacent to the toilets should be requested when the reservation is made. If the use of the lavatory is not an issue, then bulkhead seating – with its greater space for mobility – might be requested. Even with a wheelchair, connecting flights should be planned with sufficient time to meet the special needs of a handicapped traveler.

Hotel reservations should also include a notification that the guest will have special needs. Handicapped hotel rooms generally are a bit larger to accommodate a wheelchair. Bathrooms will often have stall showers rather than bathtubs. There are usually grab bars in the shower and adjacent to the toilet. Just because you are traveling, it does not mean that you have to give up the necessities (not conveniences) of home. Cruises are a great way to travel with a handi-

capped person because so much of the trip will be spent in a single venue where activities are planned for you. As with any land hotel, there are also handicapped cabins with many of the same necessities available if they are requested sufficiently in advance.

One of the perplexing issues involves the use of public restrooms if the caregiver is the opposite sex from the patient. Several facilities have family restrooms in recognition of this need. Handicapped restrooms frequently are designed to accommodate only a disabled person and caregiver. However, there are times when the only alternative is to enter an opposite sex facility. Another individual may be asked to help lead the way in order to minimize embarrassment for all concerned. Handicapped stalls in all rest rooms are generally designed to fit wheelchairs, providing a degree of privacy for all concerned – patient, caregiver, and the general public.

The extent of a patient's mobility will often determine the range of activities available to him or her. But it is important that both the caregiver and patient have a mindset that is as open as possible in order – with careful planning – to maximize the opportunities to travel that are available to them.

Finances, Economics, and Insurance:

It can be embarrassing for the Parkinson's patient to have to ask another person to help with incontinence problems. It can be depressing for the patient to have to relinquish his or her driver's license. But the greatest resistance may develop when it comes to sharing the financial aspects of one's life. This is particularly true if the caregiver is someone other than the spouse. In most families, one partner handles the checkbook, bills, and perhaps even the investments. If he or she is the one afflicted with Parkinson's, the other one had better be prepared to learn a great deal in a very short time. Virtually all of us have our own records system that works very effectively for us. But that process that we think is highly structured is likely to be a virtual maze to another who has to step in. Not all Parkinson's patients will have to give up the financial responsibilities, but the thinking process can be impacted by the illness, and missed insurance or mortgage payments will only add frustration to the medical and financial problems that are present.



Since we never know when an accident or illness may occur, it is always wise for both partners to be cognizant of a couple's financial status. Although one person may actually handle the responsibilities, both should be aware of their economic status and commitments. In this way, if it were to be necessary, the second person could step in on a temporary or long-term basis. In the case of a Parkinson's patient

who formerly was the record-keeper, the partner may have to step in because of decreased mental capacity or the inability to write a signature. It is still important that the patient be kept aware of financial activities. It will be equally important for the caregiver who suddenly is responsible not only for another person but also the family finances to learn as much as possible about investments, obligations, and the cash flow process. A record-keeping system must be established and maintained. Computer programs that trace finances, balance checkbooks, and generate reports may be of significant assistance to unraveling this economic tangle. Once data has been properly entered, reminders for various payments can be automatically prompted, minimizing the worry that something has been overlooked. Obviously, accurate input will be essential to obtaining meaningful output.

With all respect to general medical practitioners, we seek out specialized care from neurologists, urologists, and cardiologists when the circumstances so warrant. Similarly, the caregiver who is now entrusted with responsibility for the family finances should turn to other specialists to assist in making economic decisions. Attorneys and accountants are uniquely qualified to address issues of estate planning, the tax implications of financial and medical changes, and issues such as living wills and powers of attorney. A team approach may be advisable; if physical modifications to a home are recommended by a doctor or therapist, the financial implications and possible tax relief should be discussed with an accountant. It is not the time to rely on a relative's or neighbor's advice unless they are involved in those professions. Nor will this brochure attempt to substitute for such expertise. It is possible, though, to identify several documents that should be considered and discussed by the patient and caregiver with an attorney or accountant. The documents cited below vary from state to state, and they should be developed in accordance with the laws of the state where the patient resides.

A *will* identifies a person's heirs and specifies what each will inherit upon the individual's demise. A *living trust* is a revocable plan that controls asset management if the individual is disabled. A *durable power of attorney* for finance enables another individual to represent you in financial matters. *Living wills* and *medical powers of attorney* both designate another individual who can make health care deci-

sions when the individual is no longer able to make them. Precise written directions should be available so that family members are in a position to implement the patient's wishes. Specific discussions about any of these documents – including which are appropriate to an individual situation – should be conducted with a professional familiar with the laws of your state. It should furthermore be pointed out that many of these documents should be completed by the healthiest of individuals, not just those experiencing an illness. Too often, though, we delay such a process. This is not the time to drag one's feet.

Several economic decisions may vary depending on whether the patient is still working, retired, or considering retirement. As with other decisions, experts should be consulted. These may include an attorney or accountant, the administrator of your employer's benefits plan, or another financial advisor.

Both patient and caregiver should become familiar with the options which exist and the financial consequences of any decisions that are

made. These include federal and state programs, employment packages, Medicare, Social Security, and both government and private disability programs. If still employed, it is crucial to understand what benefits will continue into retirement. This can be a very challenging area to comprehend. Both the patient and caregiver, especially a spouse, must be certain they understand all the details involved. Read documents separately, and then share the understandings you each have. If there are discrepancies, clarify them. Prepare a list of written questions that can be raised with the appropriate person or agency. If the original language was confusing, you may want to receive a written clarification so that you are certain what benefits will accrue to you under different conditions.

Insurance policies can be particularly confusing. Read the policy carefully. Again, ask questions. Use toll-free numbers whenever possible as telephone calls often will be transferred from one office to another, often with long delays. Stay abreast of changes. Don't just file or discard notices you receive from pension plans, IRAs, insurance companies, and others. Be prepared to ask more questions. Understand where you stand, your rights, and the appeals processes that exist. If Medicare is your primary insurer, do you have Part B (Medical) as well as Part A (Hospital)? What supplementary coverage should you consider? Is there a plan that is right for you that will help with prescription costs? There are no set answers to any of these questions. They are all, however, valid questions that require individual answers for each patient's unique circumstances. Both patient and caregiver should know what coverages exist, how to apply for benefits, and the way to implement the appeals processes that occasionally may be needed.



Medical Resources:

Name	Telephone	Next Appointment
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Emergency:	911	
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Doctor:	_____	
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Doctor:	_____	
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Doctor:	_____	
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Doctor:	_____	
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Pharmacy:	_____	
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Physical Therapy:	_____	
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Speech Therapy:	_____	
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Community Resources:

Name	Telephone
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Support Group:	_____
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Community Center:	_____
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Church:	_____
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Other:	_____
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Family:

Name	Relationship	Telephone
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_____	_____	_____
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_____	_____	_____
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_____	_____	_____
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Financial Resources:

Social Security No.:	_____	Medicare No.:	_____
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Type of Account:	_____	Account No.:	_____
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Institution Name/Address:	_____		
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Contact/Phone:	_____		
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Type of Account:	_____	Account No.:	_____
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Institution Name/Address:	_____		
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Contact/Phone:	_____		
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Type of Account:	_____	Account No.:	_____
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Institution Name/Address:	_____		
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Contact/Phone:	_____		
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Insurance Policy:	_____	Policy No.:	_____
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Company Name/Address:	_____		
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Contact/Phone:	_____		
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Insurance Policy:	_____	Policy No.:	_____
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Company Name/Address:	_____		
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Contact/Phone:	_____		
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Investments:

Name	Number(s)	Contact
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_____	_____	_____
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Location of Important Documents:	_____		
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To share the thoughts and feelings of a Parkinson's patient, contact the NPF OCC to obtain "Dear Friends and Family," a booklet for relatives and acquaintances of the patient.

This pamphlet is a product of the National Parkinson Foundation, Orange County Chapter. Permission to reprint it – in part or in whole – by individuals or groups confronting Parkinson's disease is granted, providing credit is given to the NPF OCC.

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