



# Managing Advanced Parkinson's Disease

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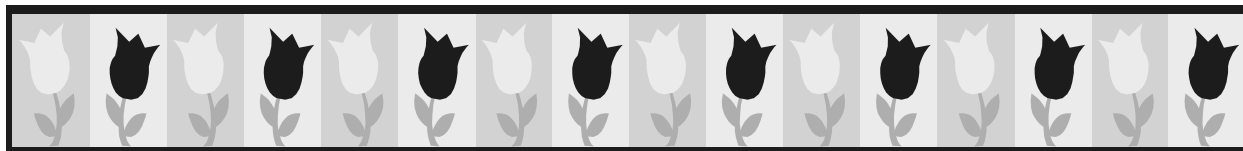
We dedicate this publication to the Parkinson community, who have shared their lives, personal experiences and insights with us over the years, and to the team of Struthers Parkinson's Center, for their creativity and dedication to improving the lives of people touched by Parkinson disease.

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## INTRODUCTION

Each person experiences Parkinson disease (PD) in a unique way, and requires a specific plan to meet his or her needs. This manual is designed for those who have developed significant complications and require assistance with mobility, personal care, and other aspects of the daily routine. Suggestions for caregiver self-care are also provided.

There may be difficult decisions and changes that occur during this stage of Parkinson disease. Both persons with PD and their family members need support, instruction, and explanation of the changes they are experiencing. Education that provides “the right information at the right time” is essential as questions arise and new problems occur.

Medications may become less effective in treating all symptoms. In advanced Parkinson disease, care is focused on safety, comfort, and the best possible quality of life.

The purpose of this guide is to provide practical suggestions for coping with complex problems; it is not intended to provide all answers or solutions. We thank the individuals with Parkinson disease and caregivers who shared their stories with us. It is our hope that this manual will bring increased awareness of continued care options for those with advanced Parkinson disease and related movement disorders.

## PLANNING AHEAD

Voices from the Parkinson community:

*"I have lived with Parkinson disease for over 20 years. My wife and I have taken steps to prepare for the future, but we are going to live the day as it is. We take it one step at a time. It's just like driving -- look ahead. See what's coming next."*

Living with Parkinson disease is a daily challenge. Taking time now to organize one's affairs and make advance preparations can help to ease the transition into the next phase. Some families find it beneficial to hold family meetings to talk about caregiving roles and plan for the future. Making sure financial and legal matters are in order also can ensure peace of mind for patients and family members.

The following are some suggested steps you can take when planning for the future.

- Keep a notebook listing medication schedules and daily routines. This can be especially valuable in the event of hospitalization, caregiver illness, or other emergency.
- Post emergency numbers near all telephones. Include numbers of family and/or friends that would need to be notified in case of emergency.
- Make sure you understand benefits and covered services included in your current insurance plan. Learn what long-term care coverage options are available.
- Maintain accurate records of assets and liabilities. A respected financial planner may be helpful when considering future needs.
- Keep important legal and financial documents in one location for safekeeping and easy access. A locked, fireproof box or safety deposit box may be best. Share this location with a trusted family member or friend.



- Consider consulting with a social worker or geriatric case manager to learn about programs, services, and care options appropriate for both current and future needs. These professionals, who are typically nurses or social workers, may be retained to help locate resources and to coordinate care tailored to individual cases.

At this time, both the person with Parkinson disease and the family begin to think about creating Advanced Health Care Directives, which are legal documents that specify wishes for medical decisions/treatment near the end of life.

These documents vary considerably from state to state. The following are some recommendations to assist you with this process.

- Seek information from a social worker or other reliable source to determine procedures in your area. They can help you create an advanced directive. It may not be necessary to visit an attorney to create these “living will” documents.
- Create a will that clearly outlines your wishes. Seek legal advice to ensure the document is valid.
- When in doubt, consider consulting with an elder law attorney. These attorneys focus on the special needs of older persons and people with disabilities. Their special expertise is targeted at protecting the autonomy, quality of life, and financial security of seniors as they age.

As friends and relatives offer their help, be ready with a list of errands or tasks that they can do. Here are some additional ways to prepare for the days ahead:

- Create back up plans for what to do:
  - if you have an urgent errand;
  - if you need home maintenance or repair;
  - if you become ill;
  - if your loved one becomes ill;
  - if you both become ill.



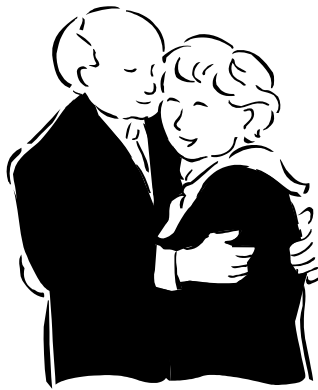
- Take advantage of home delivery for groceries, pharmacy, and other services.
- Remember: Always feel free to ask questions about things you don't understand!

## ACKNOWLEDGING CHANGING ROLES AND RELATIONSHIPS

Advancing Parkinson disease causes disruption of dreams and plans for the future, often resulting in feelings of grief, anger, and sadness. These are normal reactions to the changing situation. Acknowledging these losses, and the associated feelings, is an important step for patients and their families.

Here are some strategies to help you cope with these issues:

- Make time to enjoy the daily routine. Try to appreciate time spent together, even during mundane, everyday tasks.



- Maintain a sense of humor. Take time to share a joke or a funny story. Try to laugh at the things that don't go as planned.
- Advancing immobility, thinking changes, added stress, and caregiver fatigue may cause a loss of intimacy. While physical relationships change, closeness can still be expressed through touch, conversation, and shared times together.
- Caregivers often find themselves performing tasks normally done by the person with Parkinson disease. These added responsibilities may add further strain on the relationship. Individual or family counseling may offer assistance.
- Communicating even simple ideas may become more frustrating for both speaker and listener. Try focusing on key words, or set up a hand signal or other gesture to indicate response to yes/no questions. While communication may be difficult, it is important to allow the person with Parkinson disease to express their thoughts and ideas as they are able. A speech-language pathologist may provide additional suggestions to enhance communication.

## DECIDING WHERE TO LIVE

### Remaining in your current home

#### Voices from the Parkinson community

*"We have remodeled our home, adding railings, grab bars, heavier furniture, and chairs with arm rests. Look ahead so you will have the assistance you need. This will help you to take charge and advocate for yourself."*

Consider necessary modifications that need to be completed.

- Will a ramp be needed for outside access?
- Do floor surfaces easily accommodate wheelchair transport?
- Are the bedroom and bathroom accessible?

An occupational therapist can perform a home assessment and make suggestions.

Home health care services can provide assistance with medical and personal cares. Some of these services may be eligible for Medicare/insurance reimbursement, while others may require self-payment. Some people may also have long term care insurance; carefully check to see what these policies do and do not cover.

### Moving to a new home

**Consider both present and potential needs.** These may include help with meal preparation, medication set-up, personal care, and/or complex medical management. Ask how much these kinds of services cost.

**Spend time investigating available facilities in your area.** Compare services, prices, available staffing assistance, and experience with caring for individuals with Parkinson disease.

**Tour the facility;** make note of things like cleanliness, noise levels, odors, and safety equipment. Ask about the daily routine. Sample a meal and ask to see planned menu options. Consider revisiting a facility that interests you at a different time of day to learn more about the programs and services.



**Ask questions about ongoing care.** Can the facility comply with Parkinson medication schedules as required for individual needs? Is staffing sufficient to assist with eating, dressing and other personal cares, as needed? Do staffing levels change throughout the day and night? Are services available on weekends and holidays?

**Does the facility have specialized services** including a dietician, rehabilitation and psychological services, recreation activities, dental care, and/or special programs for those with dementia?

Some facilities offer multiple levels of care, allowing the person with Parkinson disease to stay with the same care setting even when their needs change. This may also be important for couples seeking services that apply to both individuals.

## ORGANIZING YOUR HOME

Many accidents happen in the home, and living with Parkinson disease presents added challenges to maintaining a safe home environment. A few simple steps can help reduce potential hazards and make home life easier and more enjoyable.

- Reorganize and remove clutter. Keep things you use often in a convenient location to decrease frustration and minimize added stress.



- Obtain storage containers for needed supplies. Attractive and functional bins or baskets will disguise needed equipment while maintaining appealing surroundings.

- Set up medications on a daily or weekly basis in marked containers to decrease stress and ensure accuracy.
- Remove hazardous items from the living environment. Store extra medications or toxic substances out of sight. Pay special attention to substances that may be mistaken for food items.

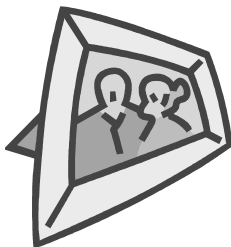


- Install a room monitor to allow listening and increase safety when in another room or area of the house.
- Schedule a home evaluation with an occupational or physical therapist for specific recommendations on home safety.

## CREATING COMFORTABLE SURROUNDINGS

No matter where we live, our surroundings are important to us. The following suggestions may help to create a comfortable, functional, and relaxing environment.

- Use soft warm colors. Colors influence the way we feel, and may contribute to relaxation and feelings of well-being.
- Fill a room with pleasing fragrance. Even though those with Parkinson disease may experience a decreased sense of smell, benefits may still be obtained through the aromas of essential oils, baking/cooking, and scented lotions or room sprays. A mist of lavender spray on a bed pillow may promote relaxation and provide a more restful sleep.



- Include meaningful objects. Photographs of family members, friends, vacations, or pets offer remembrances of favorite people and places. Mementos of achievements, celebrations, and hobbies or interests offer reminders of what is most important.
- Bring nature indoors for those who may be unable to go outdoors frequently. Plant a small garden within easy view, or purchase indoor plants and fresh flowers. Install a bird feeder at the window for indoor bird watching, or place a wind chime outside the window. Play tapes of nature sounds or purchase a small water fountain.
- Choose favorite music to set a mood. Some music may be heard as motivational or uplifting while other music may be more soothing and relaxing. Songs can also evoke strong memories, facilitating discussion and conversation.



- Use soft fabrics and blankets that appeal to the sense of touch.
- Warm washcloths, relaxing foot soaks, or a soothing hand, face or foot massage offer comfort and a connection between the caregiver and recipient.

### Voices from the Parkinson community

*"My husband found the sound of the ocean waves helped him relax during stressful times. He would often use these tapes at night to lull him to sleep."*

## CAREGIVER SELF CARE

Caregivers play a special role in the lives of persons with advanced Parkinson disease. Taking time to learn about your new responsibilities and prepare mentally can make the relationship between patient and caregiver more satisfying and fulfilling.

The following ideas can help you learn how best to provide care assistance.

- Learn proper techniques to prevent injury during caregiving responsibilities.
- Look into accessible, affordable transportation services if transferring in and out of the car becomes too difficult. A social worker or community agency (such as the Area Agency on Aging) may be able to provide listings of transportation services in your local area.
- Attend a support group designed for caregivers. Check your local senior center, health care clinic, or Area Agency on Aging to locate a group near you. To find a support group near you, visit [www.parkinson.org](http://www.parkinson.org) and click on “NPF Networks.”
- Give yourself time away – include yourself on your “to do” list.
- Write down dates you need respite support on a calendar and ask those who offer help to “sign up” for one or more of these dates.
- Learn about respite care options in your area. Find out what help is available through family, neighbors, friends, faith community or other community services. Investigate adult day programs, respite volunteer programs, or facilities that offer short-term stays in the event of caregiver vacation, illness, or need for time away. Network with other caregivers or visit with a local social worker or senior services agency to identify available options.



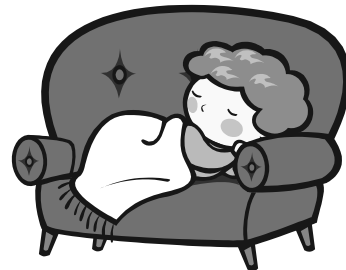
Remember to take care of yourself. Here are some additional considerations:

- Stay connected with friends and family.
- Do at least one activity you enjoy each day. Even taking a coffee break can help you “recharge your battery.”
- Avoid negative people and unrealistic expectations.



- Learn to say no to extra tasks and avoid over-scheduling!
- Get adequate physical exercise.
- Take care of your own health through regular medical check-ups.

- Rest when you can. If nighttime sleep patterns are disrupted, take advantage of daytime rest periods.



#### Voices from the Parkinson community

*“My friends and family remind me that if I don’t take care of myself, I will not be able to care for John. He attends an Adult Day Center once a week and I attend a Care partner Support Group twice a month. These things are truly a lifesaver.”*

## ASSISTING MOVEMENT

Persons with advanced Parkinson disease often need help to move within the home. Be aware that someone may require assistance at one time of the day, while being independent at another time. Offer assistance as needed. Consider making an appointment with a physical or occupational therapist who can offer proper training for caregivers, suggest appropriate aids and instruction for use, and make referrals to additional community resources.

- Before starting to move, a gentle rocking or rolling motion will help stiff muscles to relax. Avoid quick, pulling, or jerking movements.
- Offer hand-over-hand assistance as needed.
- A transfer belt placed around the waist provides the caregiver with a firm grasp and added stability when assisting with walking or transfers.



turning feet when moving from chair to bed or toilet. Visit a therapist to receive proper instruction for use.

- Coordinate efforts by arranging a signal (i.e. "1-2-3 stand") when working together. Count slowly and give adequate time to respond and assist.
- Transfer "pivot discs" (obtained at a medical equipment company) may be appropriate for those who have difficulty turning feet when moving from chair to bed or toilet. Visit a therapist to receive proper instruction for use.
- Mechanical lifts may be used if someone is unable to bear weight through the legs during transfers.
- Limit conversation when moving to allow greater focus on walking or transfers.
- Be sensitive to potential vision changes by using color contrast when choosing equipment (i.e. install a white grab bar on a dark colored wall for visual contrast).

### Voices from the Parkinson community

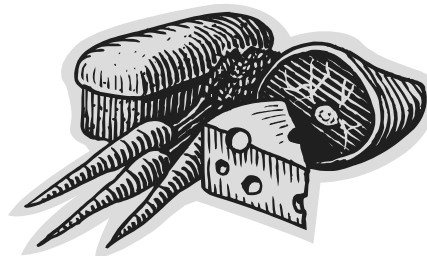
*"It is sometimes hard for Dorothy and me to remember to focus on her walking. We tend to want to continue our conversations, but have learned she has much more success if we stop talking and think about the task at hand."*

For additional recommendations, see the NPF manual, *Activities of Daily Living: Practical Pointers for Parkinson's Disease*.

## PROVIDING MEALTIME ASSISTANCE

Persons with Parkinson disease report increased difficulties with eating as the disease progresses. There are many ways a caregiver can help to make mealtime safer, less stressful, and more enjoyable. Here are a few suggestions:

- Choose foods that are easier to cut, chew, and swallow. Avoid tough, dry, or crumbly textures.
- Smaller, more frequent meals may be better, especially for those with low blood pressure, fatigue, or who note feeling full quickly.
- Alternate between liquids and solids at mealtime.
- Allow adequate time for chewing and swallowing when providing feeding assistance.
- Offer ice chips or lemon ice to aid swallowing.
- Give medications in applesauce to make swallowing pills easier.
- Do not feed, offer fluids or give medications when someone is lying down.
- Raise height of tray or plate to make eating easier, especially for those with neck immobility or vision changes.
- Consult a speech-language pathologist if coughing, choking, or recurrent lung infections occur.



Feeding tubes may be considered for those with severe problems. This is a choice that should be carefully considered with input from the individual, family members, and the health care team.

Consult with a dietician for meal ideas if food is difficult to swallow.

### Voices from the Parkinson community

*"Slowly I am learning that smaller, more frequent meals work well for Tom. He has stomach pain if he eats too much at a time or gets tired and falls asleep at the table. Meatloaf, mashed potatoes, and pour-over recipes, such as turkey ala king, seem to work well."*

## DENTAL CARE

Oral hygiene should remain an important part of the daily routine in order to prevent serious dental problems and the development of other illnesses. The following are suggestions to assist with daily care. Be sure to visit your dentist for regular cleanings, or if problems occur.

Drink plenty of fluids and use antiseptic mouthwash twice a day to decrease plaque and to kill bacteria.



Use an electric toothbrush and toothpaste to provide thorough cleaning. Mouth swabs may make oral care easier.

Drooling may become an embarrassing or unsightly problem. Be aware that dairy products and sugary foods may increase drooling.

Make sure dentures fit well and are cleaned regularly.

### Voices from the Parkinson community

*"It is hard for Adrian to stand at the bathroom sink. So we set up for brushing teeth while seated at the kitchen table. He uses his shaving mirror, a small basin, and a glass of water. I bring his electric toothbrush and paste to the table. A regular electric toothbrush was hard to handle because of its size and weight. We use a child-size electric toothbrush for better results."*

For additional recommendations, see the NPF manual, *Activities of Daily Living: Practical Pointers for Parkinson's Disease*.

## TOILETING

### Bladder Changes

Aging with Parkinson disease can affect bladder control. Your physician may recommend a visit to a urologist for evaluation and specific recommendations. The following additional tips may help.

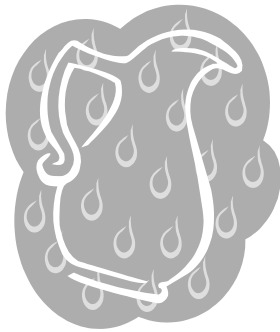
- Drink plenty of water and juices. Cranberry juice may be especially useful in helping prevent bladder infection. Symptoms of bladder infection include frequency and urgency accompanied by painful urination and foul smelling urine.



- Allow plenty of time to use the toilet.
- Work with a physical or occupational therapist to learn ways to help the person with Parkinson transfer to the toilet while avoiding injury.
- Wear a pad, shield, or other incontinence product if accidents become a problem. Try several types until you find a product that works best.
- A pad placed inside the incontinence brief adds extra absorbency.
- Use disposable or washable pads on the bed.
- Use a urinal (available for both men and women), bedpan, or bedside commode to reduce bathroom trips at night.
- Condom catheters – which fit snugly on the penis and are a user-friendly solution for urgency, frequency, and incontinence – may be helpful in preventing nighttime bladder incontinence for men. Ask your doctor, nurse, or visit a medical supply store for more information.
- Indwelling catheters may be placed in those with more significant bladder problems. Your doctor can provide more information.

## Managing Constipation

Constipation can be an uncomfortable problem and is often a significant concern for persons with Parkinson disease. Try these steps and contact your nurse or physician if bowel movements do not occur at least every three days.



- Increase fiber and fluids.
- Try more regular activity (position change and/or exercise) to help reduce constipation.
- Use over-the-counter stool softeners, as needed.

### Voices from the Parkinson community

*“Betty can get very anxious about her constipation and used to spend a good part of each day going back and forth to the bathroom. Using an over-the-counter stool softener and a prescription laxative has helped this problem.”*

For additional recommendations, see the NPF manual, *Activities of Daily Living: Practical Pointers for Parkinson’s Disease*.

## SKIN CARE

As persons with Parkinson disease grow older, their skin might become fragile and prone to break down. Suggestions to help prevent pressure sores and infection include:

- Try to change position every two hours.
- Massage lotion into the skin to prevent dryness and improve circulation.
- Observe the skin for redness, blisters, or open sores. Report skin changes promptly to prevent a more serious problem.
- Plastic coating and tapes from incontinence products can cause irritation. Avoid contact with the skin.
- Use heel/elbow protectors for added skin protection.
- If in a wheelchair, obtain a cushion to lessen the risk of getting a pressure sore.

When bathing:

- Make sure skin folds are thoroughly washed and dried.
- Consider a sponge bath for those with limited mobility or unsafe transfers to the tub or shower.
- A home health aide can offer bathing assistance if this task becomes too difficult or time consuming for a family caregiver.

When in bed:

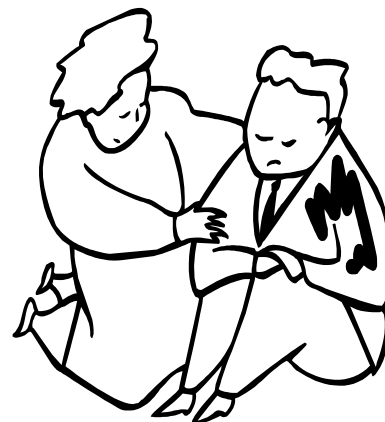
- Change clothing or bed linens more frequently if increased sweating is a problem.
- Use an “eggcrate” or alternating pressure mattress to help prevent skin pressure when in bed.



## IF SOMEONE FALLS

Accidents can happen in the best of circumstances. It may be helpful to develop a system to get up in the event of a fall. Work with a physical therapist to learn safe and proper techniques; then practice occasionally to make sure your plan works! The following are other suggestions for persons with PD and caregivers.

- If on the ground, do not hurry to get up. Make sure there are no injuries. Some people need to rest before attempting to rise. If the person who fell is unable to get up, make him or her as comfortable as possible (pillow, blanket, etc.) until help arrives.
- If able, scoot over to a heavy piece of stable furniture, then move on to hands and knees before attempting to get up.
- Consider using knee or elbow protectors for those experiencing frequent falls.
- Special clothing can be purchased with added cushion protection over hip joints. Talk to a member of your health care team for recommendations.
- Create a “back up” plan for assistance with rising. Do you have a portable phone? Lifeline or Med Alert alarm system? A family member or neighbor?



For additional recommendations, see the NPF manual, *Activities of Daily Living: Practical Pointers for Parkinson's Disease*.

## THINKING CHANGES

Not all people with Parkinson disease develop severe thinking changes, but it can be frustrating and frightening for individuals coping with these problems. It is important to acknowledge these changes, and adapt to each situation, as appropriate.

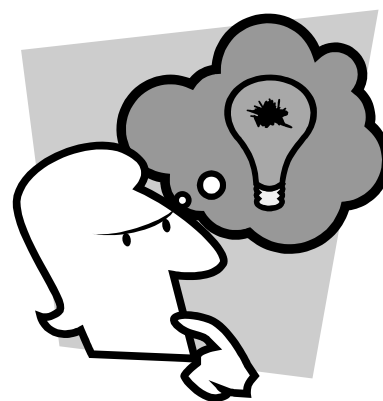
Increased forgetfulness, confusion about routine tasks, compulsive behaviors, paranoia, anxiety, or personality changes may be signals of thinking changes. Promptly report any new or sudden changes in thinking or behavior to the health care team. Medications may need to be adjusted. In some cases medications may be prescribed for depression, declining memory, frightening hallucinations, behavior or personality changes. Psychologists, social workers or other mental health professionals can provide individual, couple, or family counseling, as needed.

Be aware that thinking changes may worsen when someone is ill, hospitalized, or in an unfamiliar environment.

Provide adequate time to allow response to questions or comments. It can be very difficult and time-consuming for caregivers to provide extra time and choices, but it is an important aspect of maintaining dignity and self-esteem.

### What to Say

- Provide simple, one step instructions - too many words may be overwhelming.
- Repeat instructions throughout the daily routine for those with significant memory problems.
- Avoid confrontation. It is not helpful to tell someone who is confused or having hallucinations that they are wrong, as this usually makes the person more anxious or upset. Speak in reassuring tones and try to divert their attention from the situation, as able.
- Avoid using negative humor or sarcastic remarks, which may be easily misinterpreted.



## Things to Do

- Set up clothing or toiletries in order of use.
- Establish a daily routine and stick to it as much as possible. Use a calendar or erasable board to help provide reminders about the daily routine.
- Avoid multiple conversations or activities at the same time, as this may add to confusion or anxiety.
- Speak face-to-face.
- Try to be tolerant of remarks or actions that may be uncharacteristic of previous personality or temperament.
- Reduce unrealistic expectations. Sometimes our standards of “perfection” must be lowered.
- Register for the “Safe Return” program sponsored by the Alzheimer’s Association, which helps to identify those who may become lost or separate from their caregivers. For information, visit [www.alz.org/services/safereturn.asp](http://www.alz.org/services/safereturn.asp)



### Voices from the Parkinson community

*“Jose is often frustrated because he cannot find the words to answer questions. I try to be patient and to build up his esteem in any way I can.”*

## IDEAS AND SUGGESTIONS FOR ACTIVITIES

Finding activities for those with movement or thinking changes can be challenging. It may be difficult to find activities that are meaningful and give a sense of purpose. Some ideas for activities are reviewed below.

- Game shows, sharing a crossword puzzle, or watching a nature or history program on television may stimulate interest.
- Provide books/ videos on art, travel, architecture, or animals. For those with vision changes, books on tape or CD are good options. Use the public library, local bookstore or the Internet to find materials.
- It may be comforting for those with thinking changes to participate in familiar tasks. For example, a past office manager may enjoy sitting at a desk and sorting through papers, while a former homemaker may feel most comfortable folding towels or wiping tables.



- Pets can provide daily companionship, regular touch, and interest to the home environment. Petting, grooming, or playing with pets provides stimulation and offers both physical and mental benefits.

- Invite visits from relatives, friends, and neighbors.
- Attend adult day programs or activity programs within the assisted living/ nursing home for added socialization and stimulation.
- Maintain connections with your faith community or other spiritual care resources. Reading daily devotions or other meaningful passages, and/or speaking with clergy and other spiritual advisors, can offer strength and hope.



- Set up a “relaxation station” with personal headphones to play taped nature sounds or soft music. This may be helpful to decrease restlessness or anxiety during the day.



- Schedule rest periods throughout the day. Try to avoid excessive daytime sleeping if poor sleep at night is a problem.
- If thinking changes do not allow follow-through of exercise instructions, try “automatic response” exercises such as throwing and catching a ball, or playing balloon volleyball.
- Assist with a few extra arm and leg motions during dressing, bathing or other cares to give added exercise value.

#### Voices from the Parkinson community

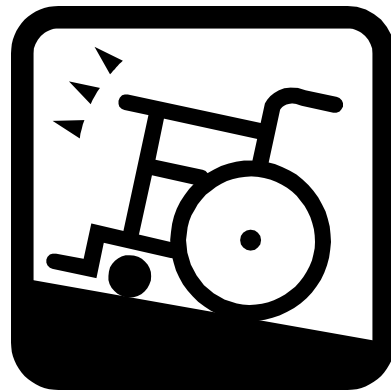
*“David perks up when relatives and friends visit. I know it’s important to invite people to our home. I have to teach myself to be less concerned about how the house looks. Frequently I remind myself that spending time with David and friends is more important than having a clean bathroom.”*

## CHOOSING A WHEELCHAIR

The time may come when use of a wheelchair becomes necessary. Schedule an appointment with an occupational or physical therapist to find out which chair best meets the individual's needs. Not everyone can safely use an electric wheelchair or scooter. Some are heavy and require installation of an electrical lift to transport in a car or van. Visit a medical supply store prior to purchase.

Check with your insurance carrier to learn about covered services in your current plan. Not all wheelchairs will be covered. The following are some options to consider.

- A lightweight wheelchair is easier to lift in and out of the car.
- A reclining chair back is helpful for those with posture changes or low blood pressure, or who need to rest during the day.
- Footrests are important, especially when a caregiver is pushing the chair.
- Elevating leg rests may be more comfortable.
- Desk-style arms may allow easier positioning at the table for eating and other activities.
- Bolsters may be used to improve sitting posture in the chair.
- Obtain a cushion that offers a firm sitting base and skin protection.
- ALWAYS lock wheelchair brakes prior to transfers. Clearly mark brake levers with colored tape for easier use.



For additional recommendations, see the NPF manual, *Activities of Daily Living: Practical Pointers for Parkinson's Disease*.

## PAIN CONTROL

Complaints of pain are more frequently noted in late stage Parkinson disease. Loss of the ability to move without help, frequent falls, or muscle stiffness may all contribute to pain. Pain may also occur with excessive dyskinesia, muscle cramping, or other medical conditions such as arthritis or neuropathy.

If experiencing pain:

- Report pain promptly to the health care team. Medication adjustments may help reduce excessive stiffness and/or muscle cramping.
- Typically, over-the-counter pain relievers can be safely used with Parkinson medications. Confirm which may be best with your physician.
- Warm packs may aid in providing pain control. Avoid the use of electric heating pads, which may cause burns with prolonged use. Microwaveable or air-activated heat wraps may offer a safer, more sustained heating with less chance for injury.
- Pain from acute injuries sustained during falls or other accidents may be better controlled with the use of ice packs to reduce pain and swelling.



- Massage provided by a caregiver or massage therapist can aid circulation and decrease soreness.
- Use cushions as needed for comfort and support. Avoid the use of too many pillows, which contribute to a flexed posture.
- Be aware that increased wandering, agitation, or unexplained crying in those with dementia may be a signal of pain.
- Visit a physical therapist for specific pain evaluation and additional recommendations.

## APPROACHING END OF LIFE

### Do Not Resuscitate (DNR)

As one approaches end of life, there should be frank and open discussion about what should be done in the event of a life-threatening emergency. A decision may be made by the patient and family to pursue a Do Not Resuscitate (DNR) order. A DNR order means that no lifesaving techniques will occur in the event of the loss of heartbeat and/or breathing. These wishes must be declared to a physician, and signed documentation must be completed. A copy of this signed document must be shown to emergency personnel. A “living will” alone is often not enough to ensure these wishes are carried out. There are resources available to help individuals write a living will, and related legal documents, taking into account each state’s laws. One example is [uslegalforms.com](http://uslegalforms.com) or 1-877-389-0141



### Choosing Hospice Care

If advancing Parkinson symptoms cause continued decline and medical complications, hospice support may be added to continue care at home or within a home-like setting. Many people think of hospice services as only for people living with terminal cancer. In fact, hospice services are available to anyone with limited life expectancy, and emphasize comfort care rather than aggressive treatment. Quality, rather than quantity, of life is stressed and hospice services may offer options to reduce caregiver stress and burnout. Emotional, spiritual and practical support is provided based on individual needs and concerns. Professional medical care continues throughout the hospice process, and many families find these support services invaluable during this difficult time.

- Talk to your physician to see if a hospice referral is indicated.
- Check to see if hospice services will be covered by insurance, and if there are any associated costs.
- Discuss hospice choices with your health care team prior to making a selection.
- Seek hospice services from an accredited agency.
- Ask for written information about available services.
- Find out criteria for inpatient or nursing home admission while in hospice.
- Ask about respite volunteer services through hospice.

## Planning Services and Memorials

Some families may wish to discuss individual choices and wishes for funeral or memorial services. While this may be a difficult conversation, it is important for those who wish to express their personal choices for type of service, music, readings, and location. Notes of these choices will be invaluable and should be kept in a secure location. Pre-arranged funeral planning services from the local funeral home, mortuary or cremation society are available to assist in this process.



## RESOURCES

National Parkinson Foundation  
[www.parkinson.org](http://www.parkinson.org)  
1-800-327-4545



Eldercare Locator  
[www.n4a.org](http://www.n4a.org)

Provides information through the federally funded Area Agencies on Aging. Speak to an information specialist about local resources by calling 1-800-677-1166.

Caregiver Resources:

Family Caregiver Alliance  
[www.caregiver.org](http://www.caregiver.org)  
1-800-445-8106

National Family Caregivers Association  
[www.nfcacares.org](http://www.nfcacares.org)  
1-800-896-3650

## RESOURCES

### Emergency Alert Systems:

Lifeline Systems  
[www.lifelinesys.com](http://www.lifelinesys.com)  
1-800-543-3546

Med-Alert  
[www.1800medalert.com](http://www.1800medalert.com)  
1-215-699-5766

Alzheimer's Association, "Safe Return Program"  
[www.alz.org/services/safereturn.asp](http://www.alz.org/services/safereturn.asp)

Hospice Association of America  
[www.hospice-america.org](http://www.hospice-america.org)

Information on Advanced Directives and Do Not Resuscitate Orders  
[www.familydoctor.org/00.xml](http://www.familydoctor.org/00.xml)

Information on Planning Funeral Services and Memorials  
[www.funeralplan.com](http://www.funeralplan.com)

National Association of Elder Law Attorneys  
<http://www.naela.com/>

National Association of Professional Geriatric Care Managers  
<http://www.caremanager.org/>

National Hospice and Palliative Care Organization  
[www.nhpco.org](http://www.nhpco.org)

Protective Clothing for People who Fall Frequently  
[www.hipsavers.com](http://www.hipsavers.com)



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