



LOUIE, LOUIE: A PORTRAIT IN PARKINSON'S

FAMILY & CAREGIVER
GUIDE

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INTRODUCTION

Louis Salzman had at least one thing in common with Pope John Paul II, Muhammad Ali and Michael J. Fox - Parkinson's disease.

Behind these famous faces, Louis Salzman is but one of the estimated 4 million people worldwide affected by this neurological neurological disorder. *Louie, Louie: A Portrait in Parkinson's* is filmmaker Cynthia Salzman Mondell's latest effort documenting her father's 30-year battle with the disease, and her family's struggle to cope with the tremendous emotional and physical responsibilities associated with his care giving.

A realistic, yet stirring look at an intimate family ordeal, *Louie, Louie* is a courageous story that many caregivers can identify with and learn from.

WHAT PEOPLE ARE SAYING ABOUT *LOUIE, LOUIE: A PORTRAIT IN PARKINSON'S*

"I wish someone had shown me a film like this in my early professional career." *Sandra Curtis, Speech Language Pathologist, Texas Women's University*

"The video *Louie, Louie A Portrait In Parkinson's* is very enlightening for Parkinson's patients and caregivers alike. It shows the struggle that those affected by Parkinson's endure on a day-to-day basis and also the trials and heartache that caregivers experience. I would recommend it for both patients and caregivers." *Etta Slaughter RN, BSN, M.Ed. Manager, Staff Development, The Visiting Nurse Association of Texas*



"*Louie, Louie: A Portrait in Parkinson's* is an extremely powerful documentary putting special emphasis on spouses and children in the role of caregivers. It is a great catalyst for group discussion and especially beneficial for neurology students in training." *Dr. Daniel Tarsy, Vice Chairman, Department of Neurology Harvard Medical School*

A NOTE FROM THE DIRECTOR

As a filmmaker, I wanted to document my father's disease. When I looked at the footage I realized the film also captured the differences and tensions between my brother, my sister and me.

When my mother died, we were left as his caretakers. Since each one of us looked at this differently, it created a lot of tension in the family.

It was sad to see this disease rob my father of his energy and physical well being. He fought hard to be independent while always maintaining a sense of humor.

However, he had a terrible fall while I was making this film and passed away. I decided to finish the film, hoping that it will help other families and caregivers who are affected by Parkinson's disease.

Millions of families have to face this challenge. *What is your duty? How do you care for a loved one who should have full-time care? Whose responsibility is it?*

Many questions arise but we do not have all the right answers. I hope by watching this film, and using this guide as a tool for understanding, people will feel more open to talk about their situations and find their own answers.

Cynthia Salzman Mondell

WHY WE CREATED THIS GUIDE

caregiver: *care·giv·er (kârgrvr) noun* 1. An individual, such as a physician, nurse, or social worker, who assists in the identification, prevention, or treatment of an illness or disability. 2. An individual, such as a parent, foster parent, or head of a household, who attends to the needs of a child or dependent adult. (dictionary.com; 2006, Lexico Publishing Group, LLC)

It is no secret that care giving is a tough job, as it drains the caregiver physically, emotionally, and financially.

But what overwhelms most caregivers is that care giving can surpass the realm of extra hours of care and support until it consumes one's life.

We must remember that the caregiver's well being is just as important as the person he or she is caring for, and have therefore designed this guide to prepare and educate caregivers about the many issues they will undoubtedly encounter.

We also hope that doctors, nurses, and social workers will find this film helpful in beginning to understand that to treat a patient is to treat a family, and family caregivers thus need just as much attention and support as the patient.

Selected Caregiver Statistics

“Informal caregiver” and “family caregiver” are terms that refer to unpaid individuals, such as family members, friends and neighbors, who provide care. These individuals can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately. Formal caregivers are volunteers or paid care providers associated with a service system.

- 52 million informal and family caregivers provide care to someone aged 20+ who is ill or disabled.
- More women than men are caregivers. An estimated 59% to 75% of caregivers are female.
- A number of studies have found that female caregivers are more likely than males to suffer from anxiety, depression, and other symptoms associated with emotional stress due to care giving.
- Other studies have found that women caregivers handle the most difficult care giving tasks (i.e., bathing, toileting and dressing) when compared with their male counterparts, who are more likely to help with finances, arrange care, and other less burdensome tasks.
- Nearly half of caregivers provide fewer than eight hours of care per week, while nearly one in five provide more than 40 hours of care per week.
- As a result of their care giving, informal caregivers are estimated to each lose an average of \$25,494 in Social Security benefits, an average of \$67,202 in pension benefits and an average of \$566,433 in wage wealth. Combined, the result is a loss of \$659,139 over a lifetime.

Family Caregiver Alliance: “Selected Caregiver Statistics”

What is Parkinson’s disease?

Parkinson’s disease is a brain disorder. It occurs when certain nerve cells (neurons) in a part of the brain called the substantia nigra die or become impaired.

Normally, these cells produce a vital chemical known as dopamine. Dopamine allows smooth, coordinated function of the body's muscles and movement. When approximately 80% of the dopamine-producing cells are damaged, the symptoms of Parkinson’s disease appear.

What are the signs & symptoms of Parkinson’s disease?

The loss of dopamine production in the brain causes the primary symptoms of Parkinson’s disease. The key signs of Parkinson disease are:

- Tremor (shaking)
- Slowness of movement
- Rigidity (stiffness)
- Difficulty with balance

Other signs of Parkinson disease may include:

- Small, cramped handwriting
- Stiff facial expression
- Shuffling walk
- Muffled speech
- Depression

Who gets Parkinson’s disease?

Parkinson’s disease affects both men and women in almost equal numbers. It shows no social, ethnic, economic or geographic boundaries. In the United States, it is estimated that 60,000 new cases are diagnosed each year, joining the 1.5 million Americans who currently have Parkinson’s disease.

While the condition usually develops after the age of 65, 15% of those diagnosed are under 50.

How is Parkinson's disease diagnosed?

The process of making a Parkinson's disease diagnosis can be difficult. There is no X-ray or blood test that can confirm Parkinson's disease. A physician arrives at the diagnosis only after a thorough examination.

Blood tests and brain scans known as magnetic resonance imaging (MRI) may be performed to rule out other conditions that have similar symptoms. People suspected of having Parkinson's disease should consider seeking the care of a neurologist who specializes in Parkinson's disease.

What is the treatment for Parkinson's disease?

There are a number of effective medicines that help to ease the symptoms of Parkinson's disease. Most symptoms are caused by lack of dopamine.

The medicines most commonly used will attempt to either replace or mimic dopamine, which improves the tremor, rigidity and slowness associated with Parkinson disease.

Several new medicines are being studied that may slow the progression. Many promise to improve the lives of people with Parkinson disease.

Can surgery help Parkinson's disease?

Surgery can ease the symptoms of Parkinson's disease, but it is not a cure. Because of the risks associated with brain surgery, it is usually not considered unless all appropriate medications have been tried unsuccessfully. When considering surgery, it is important to see both a neurologist and brain surgeon who specialize in the treatment of Parkinson disease.

From the National Parkinson's Foundation website: "Maintaining Optimum Wellness"

If You Have Recently Been Diagnosed with Parkinson's disease

It is important to recognize that the condition is one that demands adaptation, not despair.

Learning to pace yourself, prioritize goals, and make timely use of physical, occupational and speech therapies will enhance your physical, intellectual, and emotional well-being, and can make all the difference in how you enjoy life and maintain your independence.

Numerous strategies beyond the use of anti-Parkinson medications can help you achieve and maintain optimal health status.

These include such interventions as establishing an exercise program, learning the most efficient methods to perform routine activities of daily living, and improving nutritional status.

Booklets that address these subjects in detail are available free of charge from the **National Parkinson Foundation**.

Call (800) 327-4545 to obtain your copy.

It is important to seek out physicians and other healthcare providers for your "advisory team" who are both competent and compassionate.

Consider choosing a minimum of two physicians:

- A **NEUROLOGIST** who can advise you regarding adjustments in the anti-Parkinson medications
 - An **INTERNIST** or family physician that is aware of how Parkinson disease affects your overall health and can manage health problems outside the Parkinson arena.
- Primary care providers may also include physician assistants and

advanced practice nurses.

It is important that the providers in neurology/primary care collaborate to share information about your health status to ensure best care possible.

It is a good idea to maintain a personal health file at home, including:

- Dates of any major diagnoses
- Pertinent test reports
- Immunization records
- Dates of any serious illnesses or surgeries
- Allergies to medication
- List of current medications, including non-prescription drugs and supplements.

Maintaining a positive attitude is one of the healthiest things you can do in response to a diagnosis of Parkinson's disease.

At first, it is admittedly hard to have confidence that the disease is not a sentence to decline and disability.

But given time, people with good self-esteem and an optimistic attitude develop a healthy determination to cope with the illness and sustain the energy, activities, and relationships that give life meaning and joy.

From the National Parkinson's Foundation website: "Maintaining Optimum Wellness"

Where to Start: Family Caregivers

After you have assumed your role as a family caregiver, there will be many questions on your mind. Try not to be overwhelmed with all of the responsibilities and demands that you will incur, as it is best to keep everything as simple as possible.

Follow these steps to get started:

- Set up a meeting with your family and the person you will be caring for to discuss treatment options, preferences, and individual responsibilities.
- Important matters that need to be sorted out include finances (as in who will handle them and how much you are willing to spend on professional care, etc), everyday activities (cooking, cleaning, taking medicines, getting dressed, etc) and what kind of paid or volunteer services you want to use.
- Asking to address the specific needs and maintain the dignity of the patient to respect on his or her opinion. This open communication will help you understand that don't try to do everything for him/her or overlook certain activities where extra help may be needed.
- Expect disagreements and resistance to your ideas, and know that trying again at another time to discuss certain issues might be more effective.
- Understanding the situation and trying to incorporate everyone's best interests will make the process of care giving much smoother.
- Read care giving materials and contact different organizations that can provide useful information and resources.
- Talk to your doctor, nurses, and social workers for more advice.
- Find out what services and medicines your health insurance will pay for and exactly how much of the costs it will cover.

- Ask for help, get help, and accept the fact that you cannot do everything on your own!

10 Tips for Family Caregivers

REWARD yourself with respite breaks often. Caregiving is a job and respite is your earned right.

WATCH out for signs of depression, and don't delay in getting professional help when you need it.

ACCEPT the offer and suggest specific things that they can do, when people offer to help.

EDUCATE yourself about your loved one's condition and how to communicate effectively with doctors.

Be **OPEN** to technologies and ideas that promote your loved one's independence. There's a difference between caring and doing.

TRUST your instincts. Most of the time they'll lead you in the right direction.

Be **GOOD** to your back. Caregivers often do a lot of lifting, pushing, and pulling.

GRIEVE for your losses, and then allow yourself to dream new dreams.

Seek **SUPPORT** from other caregivers. There is great strength in knowing you are not alone.

STAND UP for your rights as a caregiver and a citizen.

National Family Caregivers Association (www.nfcares.org/pdfs.10_tips.pdf)

ADDITIONAL OPTIONS

Today, in many communities, resources exist to assist you and your family now and in the future. For example, support groups, counseling services and volunteer programs can help with the emotional impact of the disease or disorder and enable you to stay involved and active.

- Assistance with daily living can be provided through structured day programs, in-home support, short-term respite and other community programs.
- Legal and financial advice can guide you and your family in planning for the future. Experienced professionals can assist by providing information and arranging for services you may want.
- To find supportive services in your community, begin by calling the local Area Agency on Aging, AAA. (*You can call the national ElderCare Locator at (800) 677-1116 to find your local AAA.*) The Area Agency on Aging provides housing, medical, mental health, and social services, as well as legal and financial counseling.
- Also, look for community-based organizations that offer various elder care and/or family support services. (Visiting Nurse Association of Texas)
- Specifically, try faith-based groups, fraternal and civic groups, the United Way, hospital senior services, disease-related organizations, university nursing programs, and employer human resource departments.

FREE Programs

- Friendly Visitors
- Telephone Reassurance
- Health Insurance Counseling and Advocacy Program (HICAP)

Medicare and long-term care insurance information

- Social Security district offices (*Medicare, Medi-Cal, SSI*)
- Legal aid
- Senior centers
- Home repairs
- Hospital discharge planners (*social workers or nursing staff who help arrange home care*)
- Support groups
- Peer counseling
- Stephen Ministry-interdenominational
- Low-cost Services (*community funded programs*)
- Visiting Nurses Association of Texas programs (*help with medication routines, home maintenance, home tele-health monitoring, accompany patients to their desired destinations like the library or park, etc*)
- Meals on Wheels (*up to 2 fully-prepared meals a day*)
- Utility bill assistance
- Transportation services

Medicare covered services or fee-for-service basis

- Visiting Nurses Association-Parkinson's programs "Think Big, Speak Loud" (multidisciplinary approach includes: skilled nursing and physical or speech therapy, nutrition, social worker counseling, health aides) or other home occupational care agency with expertise in Parkinson's.
- Adult day health care
- Chore and homemaker services
- Respite care
- Visiting Nurses Association Hospice Program (Medicare's end-of-life benefit)
- Equipment rental (hospital beds, wheelchairs, etc)
- Geriatric care management
- Taking Care of Caregivers

Family Caregiver Alliance "Making Choices about Everyday Care" and "Community Resources and Self-Care" by Beth Witrogen McLeod article, from the California Department of State Health website (www.dhs.ca.gov/)

EFFECTS OF STRESS

While care giving provides a significant amount of support and special care for your loved one, it takes a lot out of you as a caregiver.

In fact, many different studies of research prove a correlation between caregiving, stress, and poor health. Balancing caregiving with work, family responsibilities, and social life can be extremely difficult, and many caregivers feel burnt out very quickly.

Financial problems resulting from missed work or having to leave your job to care for your loved one only add to the daily stress you will incur as a caregiver. The National Family Caregivers Association warns of these possible long-term health effects for family caregivers:

- **Infectious Diseases:** Stress weakens the immune system, so you are more prone to diseases like colds, the flu, or other bodily infections.
- **Depression:** Family caregivers suffer from symptoms at more than twice the rate of the general population, yet don't seek help for these symptoms because they believe it is a normal part of caregiving.
- **Premature Aging:** Chronic stress accelerates the effects of aging by actually shortening cell life. It leads to weakened muscles, skin wrinkles, and even organ failure. The study noted that this type of severe stress can take as many as 10 years off a person's life.
- **Sleep Deprivation:** Lack of sufficient rest over an extended period of time reduces the ability to think clearly and effectively. It reduces the immune system's ability to ward off illness.

- **Higher Mortality Rates:** Elderly caregiving spouses who had experienced strain had a 63 percent higher risk of death compared to study participants whose spouses did not need care.

To diminish the effects of STRESS:

- Identify what issues are causing you stress. If they can be fixed, find a good solution. If not, try to take control of the situation and make peace with it.
- Have regular medical checkups
- Exercise
- Eat healthy foods
- Maintain a good sense of humor – Laughter is the best medicine sometimes!
- Schedule some alone time
- Keep up with your hobbies (gardening, knitting, playing cards with friends, etc)
- Reach out for help
- Remind yourself that self-care is a necessity!

Tricia O'Brien, "The Stress of Family Caregiving: Your Health May Be at Risk" This article is reprinted from the Winter 2006 issue of TAKECARE! Self-Care for the Family Caregiver, a publication of the National Family Caregivers Association, www.thefamilycaregiver.org

Caregiver Self-Advocacy

Four Messages to Live By

- **Choose to take charge of your life.** We fall into caregiving often because of an unexpected event, but somewhere along the line you need to step back and consciously say, "I choose to take on this caregiving role." It goes a long way toward eliminating the feeling of being a victim.
- **Love, honor and value yourself.** Self-care isn't a luxury. It is your right as a human being. Step back and recognize just how extraordinary you are, and remember your own good health is the very best present you can give your loved one.
- **Seek, accept and at times demand help.** Caregiving, especially at its most intense levels, is definitely more than a one-person job. Asking for help is a sign of your strength and an acknowledgement of your abilities and your limitations.
- **Stand up and be counted.** Recognize that caregiving comes on top of being a parent, a child, and a spouse. Honor your caregiving role and speak up for your well-deserved recognition and rights. Become your own advocate, both within your own immediate caregiving sphere and beyond.

Patient Tips

- **As a patient, you will be faced with many burdens.** Not only must you deal with the loss of some abilities and activities resulting from your new disease or health condition, but you must also retain your sense of self-worth and dignity as you allow others to help care for you. It is a frustrating time, but with an

open mind, you may find the process and new lifestyle a little easier to manage.

Follow these tips to facilitate the transition:

- **Communicate** with your caregiver/s about your needs and abilities so that they don't try to do everything for you.
- **Be honest** if you need help. Your health is the number one priority, and this will only help your caregiver better care for your needs.
- **Be aware** that a role reversal may occur, especially between a parent and a child, and although difficult, try to adjust to this role and help out as best as you can with your family caregiver's own transition.
- If you and your family are **considering hiring a formal caregiver**, interview a few of the prospective candidates to see which personalities and caregiving methods best suit your wants and needs. After all, it will be much easier if you like the caregiver you will be spending a lot of time with!
- Keep a good **sense of humor**.
- **Stay informed** about any activities or events that pertain to your specific health condition or that relate to caregiving. Knowledge will only help you make better informed decisions about what you want and require from your caregiver.
- **Join a support group**. Sometimes just talking with someone else who can relate to your situation can provide comfort and help you put things in perspective.
- Remember that a **positive attitude** goes a long way.

- **Maintain your spirit**, have a hobby.

Excerpted from article from the National Family Caregivers Association website.

Patient Tips

Work-Related

- Can you continue to function in your job at the same level?
- If not, what part of your job has become more difficult?
- Can adjustments be made so that you can address those difficulties at work?
- Can you continue your job with different expectations?
- Is anything at work a safety risk for you?
- Can you change your job to one more appropriate to what you can do?
- Should you consider disability?

Family-Related

- What roles do you currently have in the family? (breadwinner, gardener, cook, fiscal manager)
- What roles are becoming more difficult for you?
- What about the role is difficult?
- Can the role be broken down to different tasks?
- Can you continue all the tasks, some of them, or none?
- Can someone else handle some of the difficult parts - your partner, your child or hired help?
- Is the one assuming the role knowledgeable, ready, and willing to take it on?
- Which roles are critical to the family's well being?
- Will the person assuming the new role feel overwhelmed, burdened, and anxious?
- What measures can be taken to reduce anxiety and burden?

Excerpted from the National Parkinson Foundation website in an article entitled "Living with Parkinson's Disease." While these questions are indeed helpful for Parkinson's patients, they appeal to many newly diagnosed patients who may have questions concerning their new lifestyles, and whether or not they need assistance from a caregiver.

Ask Yourself and the Patient

Some of these questions may help you and your family think about and discuss values and preferences:

- How much are we willing to spend for paid care?
- Who in the family will take charge of caregiving and/or make the arrangements for care?
- What sacrifice of money or time is too much?
- What kind of help do we need right now? What do we think we might want in the future?
- Can we get used to having a stranger in our home to help us?
- Can we adjust to someone who speaks a different language?
- Do we want some out-of-home care provided? What kind? How often? How long?

Small and very personal choices also can make a big difference. *For example:*

- How often do you want a bath? Is a shower all right? In the morning or at night?
- Would you rather have someone you know help with bathing or someone you don't know?
- Do you mind if someone of the opposite sex helps you with baths?
- What do you like to wear at home? When you go out?
- Do you like to exercise? How often?
- Do you like to go outdoors? Or do you prefer being inside, near a window?
- Would you rather be alone most of the time or have company?

Excerpted from the Family Caregiver Alliance website: "Making Choices About Everyday Care (for Families)"

Questions to Ask Your Healthcare Providers

Review this list of questions as you are planning and preparing for any interaction with the health care system (e.g., doctor visit, trip to the emergency room, hospital discharge planning session, etc.)

The questions are organized by category. Select the questions that best fit your needs. Feel free to add your own.

About Medical Care in General

- What might have caused this illness?
- What is this illness called?
- Is this illness likely to go away on its own?
- Is the pain likely to diminish or go away?
- How do you want to treat this illness?
- What are other ways to treat this illness?
- What are the risks with these treatments?
- What is the likely future of this illness with the recommended treatment? Without the recommended treatment?
- What is the time frame for the treatment?
- Is a hospital stay necessary?
- What is the expected recovery time?
- What lifestyle changes can my care recipient expect in the future?

About Medical Tests and Procedures

- Is the recommended test or procedure necessary to confirm or disprove a diagnosis?
- Will the findings of the test change the way the disease is managed?
- What are the risks involved?
- What happens if my care recipient refuses to undergo this test?
- How expensive is the test and will it be covered by insurance?

- Will the test require a change in any of the medications my care recipient is taking?
- What are the chances of inaccurate test results?
- What is the test procedure?
- How will the test feel? Will it be painful?
- How should I help my care recipient prepare for this test?
- Will my care recipient need help getting home afterward?
- Who will interpret the test results?
- Will someone call with the test results or should I phone for them?
- Can test results be sent directly to me or my care recipient?

About How the Doctor's Office Works

- What days/hours is the office open?
- How are medical emergencies handled?
- When is the best time to reach the doctor by phone, fax or e-mail?
- Which method of communication does the doctor prefer?
- Who can answer questions if the doctor is not available?
- Who can I call after hours or when the doctor is away?

Regarding the Costs of Medical Care

- What private insurance plans do you accept?
- Do you accept Medicaid/Medicare assignments?
- What costs are covered by Medicaid/Medicare? Supplemental insurance?
- What costs are not covered by insurance?
- Approximately how much can I expect to pay in the long run for treatment?

*Excerpted from Communicating Effectively with Healthcare Providers
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Questions to Ask Your Healthcare Providers

Regarding Discharge Planning

As part of the discharge planning process, many issues related to the patient's care need to be resolved.

As soon as you know your loved one is going to be admitted to the hospital, find out who is in charge of the discharge process and arrange a meeting to gather specific answers to the following questions.

- Where is the patient going to go after discharge? (*Return to the previous setting? Go someplace else temporarily? Move permanently to a new location?*)
- Who will provide additional home health care if it is needed? What about I would like to choose my own?
- Does the patient need any home health equipment? What kind?
- Do physical and/or occupational therapy visits need to be arranged?
- What additional services may be needed and for how long (e.g., Meals-on-Wheels, hospice care, housekeeping, etc.)? And where can you find the services?
- What paperwork needs to be processed to get these services lined up?
- How will the added expenses be paid for?
- What additional skills do you need to learn so you can care for your loved one properly?

Excerpted from *Communicating Effectively with Healthcare Providers*
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How to Communicate Your Loved One's Symptoms Regarding Overall Well Being, Pain and More

Overall Well-Being:

- Is the patient eating well? Any sudden changes in diet or fussiness about eating? Any sudden cravings?
- Is their weight stable? If not, what is happening?
- Are they sleeping well? Unable to fall asleep? Wakes up and is unable to go back to sleep? Has nightmares? Sleeps restlessly?
- Are they getting some kind of exercise? Suddenly doing more or less than typical?
- Is there any sign of abuse or neglect that you've noticed? If so, what is it?

General Condition

- Does the patient seem to have "slowed down" noticeably since the last visit? If so, in what way?
- Does he have any unusual bleeding? Where? How much?
- Does he seem to be breathing easily? If not, what is the quality of the breathing? *Rapid Shallow Gasping Rattling*
Other _____
- Does he cough when he eats or drinks?
- Is his digestive system working well? If not, what seems to be the matter? *Excessive gas Heartburn Diarrhea Constipation* Other _____
- Are his limbs moving as they usually do? Is he struggling to handle things?
- Have any rashes or welts appeared recently? Where? What do they look like?
- Has a mole changed shape or become dark? Has a new one appeared somewhere? If so, where?

- In general, does the treatment plan seem to be working? If not, what seems to be wrong?
- Is a particular problem the reason for this office visit? If so, what are the major symptoms or concerns?
- Are they losing their balance? Are they falling?

How to Communicate Your Loved One's Symptoms Regarding Overall Well Being, Pain and More

Pain

- Is the patient complaining about pain? What does he say it feels like? *Sharp Stabbing Dull Pounding Achy Tingling*
Other _____
- Where is it located? *All over Headache Abdomen Limbs*
Other _____
- On a scale of 1-10, with 1 being no pain and 10 being the worst pain imaginable, how does the patient rate his pain?
- How long has the pain lasted?
- Does it move around or stay in one place?
- Does it come and go, or is it there all the time?
- Does the pain seem to occur in relation to something else (e.g., eating, standing up suddenly, while reaching for something overhead)?
- Is there anything that makes the pain better or worse?
- Does pain medication help? If so, how much?

Medications

- Is the patient taking his medications on time? At the prescribed dose? If not, what seems to be going wrong?
- Are the medications effective? Is the effect incorporated with taking protein diet or doing activities?
- Is he complaining about or suffering from any side effects? If so, what are they (drowsiness, hyperactivity, etc.)?
- Does anything seem to have suddenly changed in his response to medication? If so, what is it?

- Did he stop taking a medication for any reason? If so, why and what happened as a result?

Emotional & Mental Well-being

- Does the patient seem to be as mentally sharp and alert, or has there been a noticeable decrease in mental function? What are the symptoms?
- How is his memory, both long-term and short-term? Has it changed recently? If so, in what way?
- Can he still do and enjoy activities as in the past? Has something suddenly become boring, unpleasant or even depressing?
- Does he keep hobbies and interests as before?
- Does he feel responsible for being ill and/or angry about his condition?
- Does he fear the truth and put off doctor visits based on what he thinks the doctor may say about his problem?
- Is he able to laugh and enjoy life?
- Does he seem to be more emotionally overwrought than usual? In what way? *Anxious? Depressed? Fearful? Sad? Hyped-up? Other?* _____

Spiritual Well-Being

- Are there any restrictions on treatment that need to be considered due to the patient's spiritual beliefs or practices? If so, what are they?
- Has the patient continued his usual spiritual practices (e.g., going to church, meditation, saying the rosary, prayer, using a home altar)? If not, what has changed?
- Has he started expressing doubts about faith or spiritual practices?
- Does he seem more reflective and quiet than usual? If so, does this seem to be okay?

- Is he starting to talk about wanting to "go home" in the sense of dying?

Other Conditions

Each illness has its own set of unique symptoms. Ask your doctor if there are particular symptoms that should be monitored.

Doctor's Visit Checklist

Before the Visit

- Gather your questions
- Identify current symptoms
- Check the patient file
- Call to confirm appointment

During the Visit

- Help with reporting
- Describe symptoms accurately
- Ask questions
- Record doctor's instructions
- Discuss recommendations
- Verify follow-up

After the Visit

- Review your notes
- Check prescriptions
- Discuss the visit

- Update your calendar
- Call for test results

Emergency Room Checklist

Being Prepared

- Post emergency information in a prominent place
- Have updated patient information ready to go
- Enlist a friend to be your “ER buddy” before a crisis occurs
- Pack a bag ahead of time

At the Emergency Room

- Relay critical information to the ER staff
- Introduce yourself to the head nurse and attending physician
- Get out of the way
- Wait patiently
- Review patients’ rights information while waiting
- Ask for regular updates
- Gauge your loved one’s reactions
- Listen and ask questions
- Recognize staff limitations
- Stay calm and take care of yourself

*Excerpted from Communicating Effectively with Healthcare Providers
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ADDITIONAL RESOURCES

- Visiting Nurses Association of Texas-Thinking Big, Speak Loud Program
- National Alliance for Caregiving
- National Family Caregivers Association
- Family Caregiver Alliance
- Johnson & Johnson/Rosalynn Carter Institute Caregivers Program
- Caregiver.com
- Everyday Warriors
- Caring Connections
- Caring Today
- Faith in Action Volunteers Caregiving
- Strength for Caring
- Caregivers Marketplace
- Caregiving.com

- Well Spouse Foundation
- Medicare
- The Medicine Program

- Parkinson's Information & Exchange Network Online (P-I-E-N-O)
- AARP

ADDITIONAL RESOURCES (continued)

- American Society on Aging
- National Association of Geriatric Care Managers
- Eldercare Locator
- National Family Caregiver Support Program Resource Room
- The National Private Duty Association (NPDA)
- Meals on Wheels
- Arch National Respite Network and Resource Center
- Gilbert Guide
- Mr. Long Term Care
- We Move
- American Parkinson Disease Association, Inc.
- Michael J. Fox Foundation
- National Parkinson Foundation
- Parkinson's Disease Foundation



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ABOUT MEDIA PROJECTS

Louie, Louie: A Portrait in Parkinson's won a Gold Remi award at the 39th Annual WorldFest-Houston International Film Festival, one of the most significant independent film festivals in North America.

Director Cynthia Mondell also received a CINE Golden Eagle award for the film, which is recognized internationally as a symbol of the highest production standard in filmmaking and videography.

Louie, Louie: A Portrait in Parkinson's was produced with contributions from the Harold Simmons Foundation, the Michael L. Rosenberg Family Foundation, HRH Foundation and Irving Cable.

Established in 1978, Media Projects, Inc. is dedicated to producing and distributing films addressing topics of social concern. MPI films have won numerous national awards, been selected for prestigious theatrical screenings in the United States and abroad, and have aired on PBS and national cable networks.

Media Projects finances its work through tax-deductible contributions and major contributors have included:

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