

curePSP®
UNLOCKING THE SECRETS OF BRAIN DISEASE®

Carepartner Guidebook

2020 Edition



TABLE OF CONTENTS

- MANAGING CARE AND GETTING PROFESSIONAL SUPPORT 1**
 - Building Your Personal Advisory Team 2*
 - The Carepartner Plan: A Guide to Assessing and Prioritizing Your Needs 4*
 - Understanding Advance Healthcare Planning 8*
 - Compassionate Allowances 14*
 - The Social Worker’s Role 14*
 - Understanding Levels of Home- and Community-Based Services and Residential Care 17*
 - CurePSP Support Groups 22*
 - When to Stop Driving: The Hard Conversation..... 24*
 - Understanding Palliative and Hospice Care 26*
 - Caring from a Distance 30*
 - Respite Care 31*

- BEING A CAREPARTNER 34**
 - Keeping Families Strong 35*
 - Talking to Children and Grandchildren 37*
 - Facing Loss and the End of the Caregiver Role 41*
 - The 7 Deadly Emotions of Caregiving 44*
 - Make Meaning to Stay Positive 47*

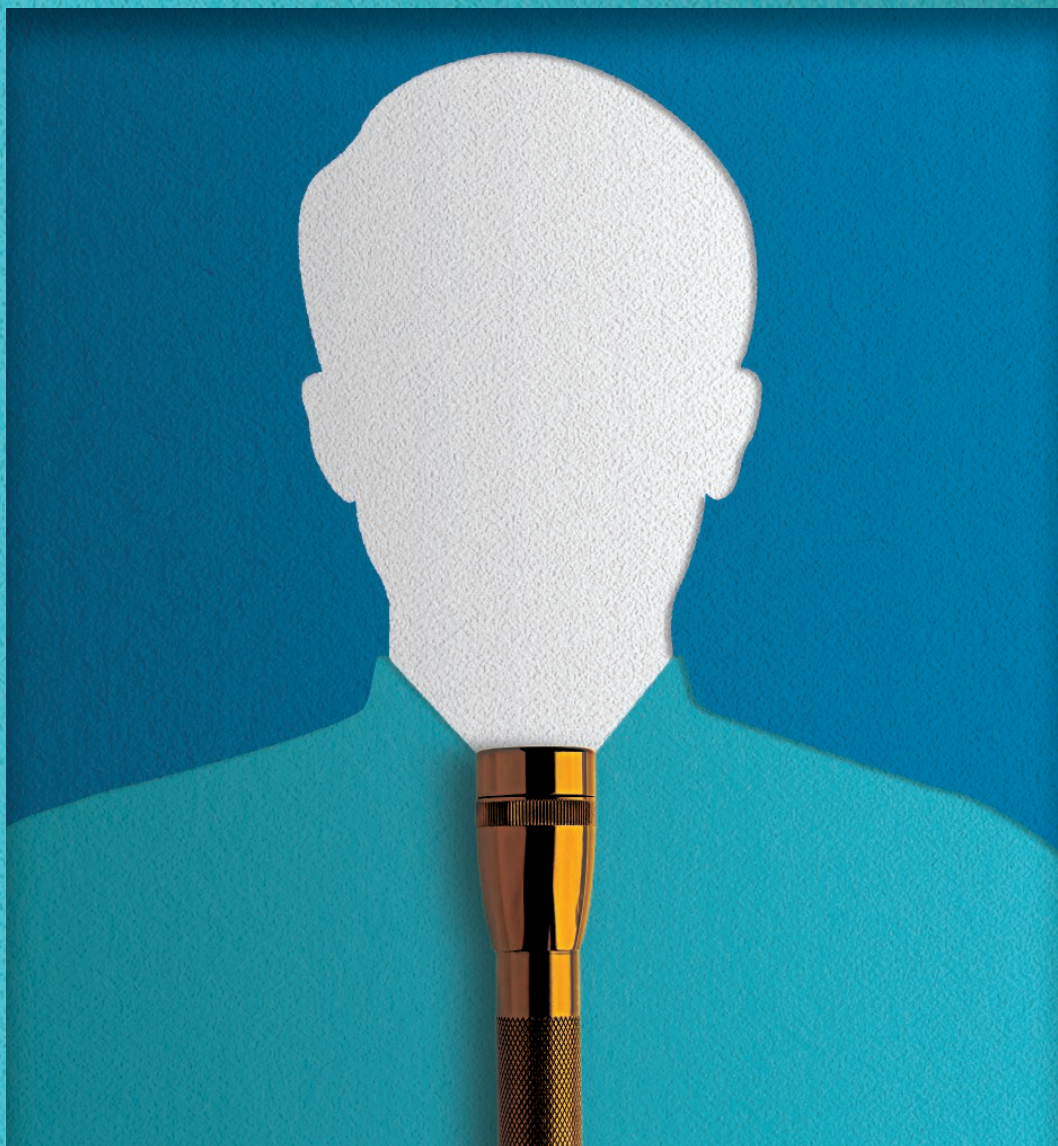
- MAKING PLANS 49**
 - Estate Planning 50*
 - CurePSP Brain Tissue Donation Program 53*

- FROM OUR FAMILIES..... 57**
 - I. Patience 58*
 - II. A Carepartner’s Comments to the 10/23/2009, Chicago CurePSP Conference ... 59*
 - III. Products That I Remember Fondly, and Newer Ones from 2018 62*
 - IV. Caregiver Checklist 63*
 - V. Products and Practical Pointers Based on Experiences with Eileen 64*
 - VI. Tips for Taking Care of Your Loved One’s Emotional Needs 65*
 - VII. Taking Care of Yourself 66*
 - VIII. Desirable Attributes of Home Health Agencies, Aides, and Nursing Homes 67*
 - IX. A Life Well Lived 68*
 - X: Thoughts about Hospice 69*

PART ONE

Managing Care

and Getting Professional Support



Building Your Personal Advisory Team

Diane Breslow, MSW, LCSW

Who doesn't want to feel in control?

When facing uncertain and unfamiliar territory—illness, trauma, and transitions—most people fare better if they receive information (not too much but not too little either) and if they can develop a plan (albeit a flexible one). I once read a quote from a family member of a loved one with a neurodegenerative disorder: “The worst day of this disease was the day of diagnosis. The best day was the day that we, as a family, understood that we could find ways to handle it. What we needed was a sense of control—and some power.”

That sense of control can come from many different realms, people, and perspectives, both professionally and personally. First we will look at the why and the how of building your core healthcare team. Then we will explore other sources of support that can help to fortify and sustain you along your journey.

The Rationale for Team Care

It is an understatement to say that PSP, CBD, and MSA are intricate, complicated diseases. Movement disorders involve so much more than disorders of movement. Besides affecting mobility, these diseases have an impact on the autonomic nervous system—activities of daily living, sleep, mood, emotional well-being, communication, cognition, and social and family relationships. The diseases are chronic, meaning that they continue over a long period of time. In addition, they are progressive, which means that symptoms increase over time. Given this complexity and impact, we can easily understand that a single healthcare discipline cannot address all of an individual's and family's concerns. Rather, these diseases must be treated holistically. Clearly, medical diagnosis and treatment are the foundation upon which you will build your team. After you have established a relationship with a movement disorders neurologist, many other healthcare disciplines, types of interventions, support, and support programs will play a significant part in treatment and management.

The Goal of Team Care

The overarching goal of team care is the delivery over time of the right blend of clinical care, information, education, emotional support, and programs designed to improve quality of life. Ideally, this kind of interconnected or holistic care is provided in a coordinated, seamless manner—across settings, professional disciplines, and time. In many instances, team care requires an individual (carepartner, family member, or care manager) who is designated—and dedicated—as the point person, communicator, and keeper of appointment schedules, team members' contact information, patient information, etc. Last but not least, you want a care team that views patients and families as essential partners in their own care. In other words, you want to participate in the development of a continuous care plan and in ongoing decision-making.

The Professional Healthcare Team

Hopefully this Guidebook gives you insight into the roles of multidisciplinary professionals who will make up your team. You will not be involved with each of these specialists all at the same time. However, at some point in the course of the disease, you will likely encounter them. Therefore, in this book, experts in many of the relevant professions have contributed their knowledge. Those professionals on your team may include:

- Movement disorders neurologist (specialist) and their clinical nurse
- Primary care provider (PCP)
- Physical therapist (PT)
- Speech and language pathologist (SLP)
- Nutritionist/Dietician
- Clinical social worker (MSW)
- Occupational therapist (OT)
- Pharmacist
- Psychiatrist and/or neuropsychologist
- Neuro-ophthalmologist

Becoming a Partner in Your Care

There are steps you and your loved one can take to feel more comfortable as a partner and collaborator on the care team.

- Learn about each team member's role.
- Find out how to access their professional services.
- Acquire their contact information.
- Become educated about the disease and its management.
- Ask questions.
- Encourage family or friends to accompany you to medical and therapy appointments and your support group.
- Establish communication with your team.
- Obtain the name of your particular point person on the team: the person who will either answer your questions or triage them to the team member who can best respond.

Your Neurologist Visit

To make the most of your time with the movement disorders specialist, come to the appointment prepared:

- Bring a list of all current medications, including dosages and times.
- Inform the neurologist of health and family changes, or hospitalizations, since the last visit.
- Write down—and bring—questions and health concerns.
- Ask for explanations of medical terms, medication changes, and recommendations.
- Ask about referrals—such as rehabilitation therapist, social worker, and classes—even if, or especially if, the doctor does not raise the subject.
- Take notes.
- Provide your neurologist with the contact information of your primary care physician.
- Before leaving the appointment, make sure you understand the plan: medication schedule and changes, potential side effects, referrals, and date of return visit.

MANAGING CARE (continued)

Expanding Your Support Network Beyond Healthcare

Begin to consider that your team is made up of everyone who has, or could potentially have, a part in helping make your lives as patient or caregiver better, fuller, or easier. This support system may include family members, friends, neighbors, an exercise teacher or trainer (for patient or carepartner), volunteers, clergy, a paid caregiver, and respite care. Your growing network may also consist of various kinds of groups, such as music, dance, or exercise classes; a support group; service or advocacy organizations; and religious affiliations.

As a carepartner, do not be afraid to ask for help. Many people want to help but may not know what you need or even how to approach the subject. Determine which obligations—whether in caregiving or in day-to-day life—you could comfortably relinquish. Then, make a plan to do just that. Write down the names of people who might assist you, and for which activity or task. It may take a while, or even be an ongoing endeavor, for you to coordinate this type of plan. But it will be well worth it.

Conclusion

Remember that your loved one's care and your own self-care are continuous and ongoing. Over time, you will integrate new professionals, friends, and volunteers into your lives. Some people may assume a lesser role; others, a greater role. Your support network is fluid yet a constant in your life.

The Carepartner Plan: A Guide to Assessing and Prioritizing Your Needs

4

Diane Breslow, MSW, LCSW

It is likely that you, as a family caregiver, provide full-time or close-to-full-time help for your loved one. More than likely, you are involved in assisting your loved one with activities of daily living and medical tasks as well as maintaining a household; shopping and preparing meals; organizing records, documents, and appointments; transporting your loved one to health and rehabilitation; keeping up with social and family relationships; and many other tasks. You are likely providing this care in your home. At the same time, you may be working, raising children or grandchildren, or dealing with your own health or personal issues. Caregivers have an enormous, and often underappreciated, job.

Although the caregiver journey is unique for each individual caregiver, it carries common stresses, concerns, fears, and rewards. Research from the National Alliance for Caregiving shows that the top four caregiver concerns are:

1. Keeping your loved one safe
2. Managing your own stress
3. Finding activities that will engage the person with the illness
4. Carving out time for one's self

Research also reveals that, when caregivers are asked what they want, the majority respond that they want information about coping with being a caregiver. This information takes several forms: knowledge about the disease, comfort with the caregiving role, and dealing with stress.

Caregiver burden is defined as: “The strain or load borne by a person who cares for an elderly, chronically ill, or disabled family member or other person... The point where the experience is no longer a viable or healthy option for either the caregiver or the person receiving the care.” (Kasuya, RT, Polgar-Bailey P, Takeuchi R. Caregiver burden and burnout: A guide for primary care physicians. *Postgraduate Medicine* 1000; 108(7)119-123).

We also now know for a fact what Dr. Nicholas Christakis from Harvard wrote in the *New England Journal of Medicine*, Feb. 16, 2006: “Certain diseases take an especially heavy toll on the health of the spouse-caregiver. It is the **disablingness** of a condition, not necessarily a terminal nature of the condition, that contributes to caregiver stress.” The Carepartner Plan is designed to help you, the carepartner, to understand and manage your own particular caregiving situation so that the role can continue to be—or return to being—a healthy and viable option for you.

The Carepartner Plan is based on the premise that caregivers’ needs comprise seven broad categories whose order of importance will vary as circumstances and disease symptoms change. Therefore, you should revisit and re-evaluate the seven areas to determine your own particular needs at any given time. The seven categories include:

Disease Education

- Understanding the symptoms and how the diagnosis was made
- Treatments and symptom management
- The impact of the disease on the patient’s and family’s everyday lives
- Resources and sources of information
- What does it mean to be a carepartner?

Time Management

- Make a daily and weekly list of things to do. Make it manageable and realistic.
- Prioritize—do the most important or difficult things first. Check off what’s done.
- Do several errands at one time, rather than going on multiple, time-consuming outings.
- Take a small task with you if you are going someplace where you may have to wait.
- Delegate what can be delegated.
- Forget unnecessary tasks.
- Take a break when pressure gets too great, or as a reward.
- Don’t do so much in one area that you cannot be effective in another.
- Break large tasks into smaller, more doable parts.
- Establish and try to maintain routines.
- Recognize that you will have to expend some amount of time and energy on the unexpected and on things beyond your control.

MANAGING CARE (continued)

Self-Care, Health, and Respite

- Build in quality time for yourself—1 to 1½ hours a day—and protect it.
- Keep up with your own needs, hobbies, and regular activities. Hold on to your own sense of self.
- Exercise. It leads to better sleep, decreased tension and depression, and increased energy.
- Eat a balanced, nutritious diet. Drink water.
- Recognize when you are stressed.
- Get enough rest.
- Take time to relax.
- Maintain a sense of humor.
- Get regular checkups and keep your own medical appointments. If you provide a lot of physical, hands-on assistance to your loved one, take particular care of your back. Ask a physical therapist for tips on lifting and see if there are assistive products that can help you or the person with the illness.
- Think about your future beyond the caregiving role. What goals do you hope to achieve, and how can you achieve them? Can your care recipient help you achieve them?
- Know your limits, set limits, and bring in outside help (family or paid worker) so that you can take a break.

Emotional Support and a Support Team

- You alone can do it, but you cannot do it alone. Caregiver or carepartner is an identity or role that you grow into.
- Share the care: Emotional support can be derived from obtaining physical and concrete help, as well as emotional help.
- Develop your coping skills, ways to express and release difficult emotions. Give yourself permission to feel sad, frustrated, or irritated—but also to enjoy. Try not to be critical of yourself in moments of anger. Give yourself credit, not guilt. Grieve. Laugh. Love. Hope. Forgive your mistakes. Focus on the present, the needs and rewards of the day. Use positive self-talk, such as “I am doing a good job.” Know that it’s okay to cry. Write about your experiences and feelings: Research shows that writing helps.
- Develop your emotional and spiritual support network, including your healthcare team (physician, nurse, social worker, rehab professionals), your family, friends, neighbors, support group and individual support group members, clergy, volunteers, and online support forums. Seek comfort from your faith, faith community, and spiritual practices. Find meaning, insight, understanding, and your own inner strengths. Adjust your expectations: Life and you are not perfect. Accept changes as they occur. Get help if necessary. Remember, it is a strength, not a weakness, to ask for help, including emotional help or counseling. Each person experiences depression in a unique way. It is important to take seriously any symptoms you experience that could signal depression. You should not feel embarrassed or ashamed. There are several core symptoms you should be aware of:
 - Sleeplessness
 - Loss of appetite
 - Difficulty concentrating
 - Feelings of hopelessness and worthlessness
 - Feeling slowed down or restless inside
 - No interest in once pleasurable activities
 - Thoughts of death or suicide

If you think you may be depressed, talk to a doctor or mental health professional about your symptoms. Find a supportive professional that you trust and with whom you feel comfortable. In most cases, depression is effectively treated with antidepressant medications, psychotherapy, or a combination of both, plus activities such as regular exercise, spirituality, supportive social interactions, and meditation.

Your Relationship with the Person with the Diagnosis

- Maintain open communication.
- When conversing, remove or turn off loud and distracting noises.
- Express love and appreciation, and also concerns and feelings of frustration. Don't let negative feelings transform into interfering resentments.
- Share special time together apart from caregiving tasks.

Medical, Financial, and Care Decisions

- Define and clarify issues, whether around family participation in caregiving, advance directives, or long-term care options.
- Devise steps for carrying out plans.
- When making decisions about giving hands-on care, ask if your decision promotes your loved one's independence: Do not confuse caring with doing.

Community Resources

- Physical and practical assistance and products
- Caregiving and disease-specific associations
- Educational materials and seminars
- Legal, such as Power of Attorney for Health Care
- Financial, such as disability assistance or medication assistance
- Professionals, such as specialist physicians, nurses, therapists, social workers, and clergy

Conclusion

Once carepartners have identified their concerns, they can then more easily move on to a step-by-step plan.

In summary:

- Using the seven headings described above, rank your needs and concerns in priority order.
- Address your most pressing needs first. View the other categories with less urgency and plan to revisit them at a later date.
- Think about and jot down action steps that you can take.
- Discuss your ideas with people on your healthcare team and with those family and friends who are closest to you.
- Devise a step-by-step plan.
- Implement the steps—with help from others.

Understanding Advance Healthcare Planning

Diane Breslow, MSW, LCSW

CurePSP is committed to providing its constituents—patients, families, caregivers, and healthcare providers—with up-to-date educational information about topics relevant to living with neurodegenerative disease.

It is of utmost importance that patients understand the disease and its potential treatments, decide their wishes for future care—including end-of-life care—and discuss these wishes with their family.

The earlier in disease progression these topics are addressed, the better for everyone—patient, family, and healthcare providers. The benefits of Advance Planning are many-fold—for example: a comfort or freeing-up feeling in having decided one's plans for possible disease complications; diminishing of fears through the course of the disease; and helping the family and the team stay on the same page in their ability to honor and carry out the patient's wishes.

This article will help you recognize possible late-stage treatment options for neurodegenerative disease, as well as understand the various kinds of planning documents.

Education about Advance Directives: Making the Case

A 1997 study in the *Annals of Internal Medicine* (Hoffmann et al.) found that most people do not communicate in advance to their families and healthcare providers their wishes about treatment. Research published in the July 2017 issue of *Health Affairs* demonstrates that statement is still true. In fact, only one-third of adults in the United States have advance directives (ADs). Furthermore, people living with chronic illnesses were only slightly more likely than healthy individuals to express their wishes in written documents.

Research studies consistently report that receiving education about advance directives significantly results in increased completion of such documents. (*JAMA 1994, University of Massachusetts Amherst College of Nursing 2013, General Medicine 2014, Journal of Pain and Symptom Management 2017*, among others).

It is up to each individual to decide if and how they want to think about their medical destiny. Education is key to ensuring that medical-legal issues are discussed, understood, and acted upon.

Myths and Facts about Advance Directives

Myth: Federal law requires that every person have advance directives.

Fact: The Federal Patient Self-Determination Act of 1991 obligates healthcare institutions and professionals to ask patients if they have advance directives and to provide information and education about advance directives.

Myth: Most seriously ill patients have discussed cardiopulmonary resuscitation (CPR) with their doctor.

Fact: Most patients have not discussed CPR with their physician. Yet, the vast majority want to have this discussion.

Myth: An attorney is required to complete one's advance directives.

Fact: Legal forms are required, but the services of a lawyer are not. The conversation is best started with one's physician and closest family members or trusted person. An attorney can be helpful in drafting personalized documents.

Myth: Some states in the U.S. do not recognize advance directives.

Fact: Advance directives are recognized in all 50 states. However, states differ regarding requirements such as number of witness or necessity of a notary. Some states maintain registries that allow quick access by agents and healthcare providers.

Myth: Advance directives should be kept in a safe deposit box with other important papers.

Fact: A copy of your ADs should be readily available at home. Patients should also give a copy to their physicians and proxy (agent). It is a good idea to make extra copies in the event you need to be admitted to the hospital.

Myth: With an advance directive in place, the person gives up control.

Fact: Drawing up an advance directive gives you the opportunity to decide, state, and put in writing the end-of-life care you want, thereby helping your agent represent your choices when the time comes.

The Basics

So, what are advance healthcare directives? They are documents designed to ensure that a person's wishes—to accept or refuse treatments—are met through written directives. Healthcare institutions (hospitals, home health, nursing homes, etc.) are legally obligated to: 1) ask patients if they have advance directives, and 2) provide information and education about advance directives. It is up to each one of us to decide, while we are well and capable, how we will want unexpected medical events to be handled. By exercising our freedom to decide for ourselves our fate or the course of actions, we greatly decrease the chances of an arbitrary exercise of outside authority in determining our futures. Our aim in having ADs is to give us maximum control of our lives and our futures, and to provide peace of mind to our loved ones.

Making healthcare decisions involves trying to understand a lot of information that may be confusing, daunting, and scary. There are multiple issues to consider and a variety of documents to obtain, draw up, sign, and periodically review. The definitions and explanations below present an overview of the documents and will help you decide which ones are pertinent for you. The Resources section below will guide you to more detailed information and next steps.

Values History

A Values History Form is designed to help individuals reflect upon their own personal value system before and while making healthcare decisions. Approaching advance directives from a values perspective enables people to make healthcare choices in line with their values. The intention of a Values History is not only to help an individual understand their own wishes regarding advance care planning, but also to convey one's ethics, views, and principles to family members. In that spirit, values questions include topics such as your overarching attitude or philosophy toward life and health, your goals, what makes your life feel worthwhile, what you fear, what you enjoy, your current health and health challenges, your views about independence-dependence, your role in significant relationships, your spiritual or religious beliefs and how those affect your feelings about illness, your attitudes and relationships with your healthcare providers, and more.

Examples of different Values forms include:

- Values History from the University of New Mexico Center of Health Law and Ethics
- *Ethical Wills: A Modern Jewish Treasury* edited by Jack Riemer and Nathaniel Stampfer (Schocken Books)
- *Ethical Wills & How to Prepare Them* edited by Jack Riemer and Nathaniel Stampfer
- *Ethical Wills: Putting Your Values on Paper* by Barry K. Baines, MD

MANAGING CARE (continued)

Resuscitation Orders

In the event that one's heart ceases to beat or is in a life-threatening abnormal rhythm, an individual has the right to choose what, if any, type of resuscitative intervention they would accept.

Do Not Resuscitate (DNR), also called Do Not Attempt Resuscitation (DNAR) and Allow Natural Death (AND)

Do Not Resuscitate orders are doctor's orders instructing medical personnel, nursing, and hospital staff not to try to return your heart to a normal rhythm by any means: cardiopulmonary resuscitation (CPR), electric shocks (defibrillation), or medications. On the other hand, a doctor may specify in writing the specific means by which you would or would not want to be revived. In addition, Do Not Resuscitate orders mean that you refuse life-support measures.

These orders require the patient's consent and signature, two witnesses, a physician's written order and signature, and inclusion in the patient's medical record. If a hospitalized patient does not want CPR under any circumstances, the physician is obligated to write the DNR order, thereby permitting nursing staff and code teams to withhold CPR. In out-of-hospital situations, such as at one's home or in a dedicated hospice facility, many states require a specific out-of-hospital form to be completed and signed by the patient or patient's proxy and the physician.

Do Not Intubate (DNI)

Do Not Intubate orders instruct medical personnel of a nursing facility or hospital that the patient does not want to be put on a ventilator, or breathing machine, to prolong their life.

Living Will

A Living Will allows one to put into writing their wishes about future medical treatment should one have a terminal condition (incurable, irreversible, and where death is imminent) and be unable to communicate. The Living Will outlines one's desire to withhold "heroic measures." It usually addresses resuscitation and life support; however, it may cover more preferences and interventions. For example, Living Wills can specify directions about particular death-delaying procedures one wants or does not want, such as artificial life support, transfusions, and dialysis. The key points to remember about Living Wills are: 1) They refer to a terminal condition; 2) They do not designate a patient's spokesperson or proxy.



Durable Power of Attorney for Health Care (DPOA-HC)

The Durable Power of Attorney for Health Care is a signed legal document that designates and authorizes an agent to carry out a person's healthcare and life-support wishes at any time in the future that one loses the ability to speak or make one's own decisions. Every state in the United States has passed a state law recognizing Durable Power of Attorney for Health Care. However, certain regulations may differ from state to state, such as whether a notary is required.

In addition to naming a healthcare agent, the person who is establishing a DPOA-HC also identifies alternate or successor agents who will serve—one at a time, and in listed order—if the original agent can no longer function in the role. A DPOA-HC can include instructions regarding life-support measures, artificial nutrition (tube feeding and what type) and hydration (intravenous fluids), mechanical ventilation (tracheotomy), comfort care, if or when to end life-sustaining measures, CPR, anatomical organ gifts, and disposal of remains. It is crucial that anyone who is completing a DPOA-HC discusses their wishes with their chosen agent and successor(s). If those people indicate that they would not be comfortable expressing your personal wishes, then you need to choose another agent, or successor, as the case may be. If the time comes that your designated agent is unsure of your wishes in a specific situation, that agent is required to speak in your “best interest.”

Remember to periodically review, update (if necessary), re-date, and initial the original document.

DPOA-HCs can be ended any time by informing your physician and agent of your decision and destroying the document, or by drafting, signing, and dating a new one.

Practitioner Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOLST)

POLSTs are signed practitioner's orders. They act as standing medical orders and apply to all healthcare personnel (EMTs, emergency room personnel, etc.) and in all settings (homes, assisted living facilities, nursing homes, etc.). The type of practitioners who can sign the POLST varies by state, and may include a physician, advance practice registered nurse, nurse practitioner, and physician assistant. POLSTs provide guidance about one's care near the end of life, allowing healthcare personnel to act immediately—and in line with your wishes—in an emergency. POLSTs spell out what specific care should be administered or withheld *at the present moment in time* for a specific patient, as directed by a physician. The POLST Paradigm is in effect in most states of the United States.

Because these are signed medical orders, they are portable in states where POLST programs have been legislatively determined. This means that all healthcare facilities and emergency service providers in the region have agreed to recognize and abide by the orders, regardless of where the document was originally signed. POLST is particularly relevant to patients expected to transition from one healthcare setting to another.

The form is completed after a careful discussion between the doctor and all parties involved. The form contains three sections: cardiopulmonary resuscitation, medical interventions, and artificially administered nutrition. The patient can choose no nutrition by tube, defined trial period of tube nutrition, or long-term artificial nutrition by tube.

For more information, please see the POLST website: www.polst.org.

MANAGING CARE (continued)

Mental Health Treatment Preference

This type of directive asks you to state whether you would allow electroconvulsive treatment (ECT) or psychotropic medicine if you have a mental illness and are unable, at the time, to make these decisions for yourself. In addition, you can express whether you will accept admission to a mental health facility for up to a certain number of days (for example, 17 days). You can name someone to speak for you. These orders are written and have an expiration (such as, three years from signature date). They require witnesses. Mental health treatment directives can be canceled in writing as long as you are not receiving mental health treatment at the time of cancellation.

It is important to note that not all states have a mental health treatment advance directive, and requirements may vary by state.

Guardianship

A guardian is a legally responsible individual who is court-appointed—on a limited-time or full-time basis—when an individual is not able to make their own decisions and there are no advance directives and designated healthcare proxy, or no next of kin (commonly referred to as surrogates). Other instances that might necessitate a court-appointed guardian include families in which multiple first-degree relatives cannot agree—even with mediation, or where a next of kin is clearly acting in their own self-interest and not that of the patient. Fortunately, formal guardianship is rarely required.

Points Pertinent to PSP and Related Diseases

Patients and family members often put off what they view as the morbid discussion of whether artificial nutrition and hydration (ANH, or tube feeding) should be used if swallowing problems or advanced dementia keep the patient from eating and drinking normally. Without the discussion, however, a crisis situation can develop. If the person with PSP is unable to make their wishes known, then it is left to the Durable Power of Attorney for Health Care to decide whether or not to place a feeding tube.

If the person with PSP is competent and able to make care decisions, then the question of whether to accept ANH can be made based on individual circumstances and beliefs. But what if the patient is no longer able to make personal decisions and has not previously completed a Durable Power of Attorney for Health Care? The person acting as the health decision surrogate (spouse, partner, adult child, sibling, close friend) may struggle with the ANH decision and not have much time to think about it. The following information may be of help.

If ANH is being suggested because the patient is at risk for aspirating or has had a bout of aspiration pneumonia, it is important to know that the feeding tube will not prevent bacteria-laden saliva and nasal secretions from getting into the lungs and causing infection. In other words, patients could still die of pneumonia.

Placing a feeding tube in a severely demented person can result in the patient trying to pull the tube out and needing to be physically restrained. This can worsen any agitation the person might have and may lead to the use of sedative medications. In the Cochrane review done in London, doctors searched for evidence that tube feeding improved the quality of life for people with advanced dementia—but could not find any. They, in fact, found some evidence that tube feeding increased mortality and morbidity, and reduced quality of life.

Decision makers also worry that by not choosing ANH, they are dooming the patient to a long and painful death. Reports from conscious dying patients indicate that thirst and appetite decrease naturally at the end of life. Conscious elderly patients slip quickly into a coma that is free of pain; observation of unconscious patients indicates that their dying process is quite peaceful. If the body is shutting down in preparation for death, artificial hydration—the process of giving intravenous fluids—can actually cause distress. The body is unable to rid itself of excess fluids at this time, and they can build up in the lungs, making it hard to breath.

In an article that appeared in the *Journal of General Internal Medicine*, the authors point out that we seem to have lost sight of the difference between a person who dies because they stop eating and drinking, and one who stops eating and drinking because of the natural dying process. Hopefully in the future, we will have clinical studies that define more clearly when the use of ANH in advanced PSP adds quality as well as quantity to a patient's life and when ANH inhibits the natural process of dying.

Summary

With this basic information in hand, we hope you will discuss and draw up your wishes in conversation with your family, your physician, and an experienced social worker or nurse. Doing so will provide you with control over decisions about your care even if you are unable to communicate in the future and will provide your family or agent with valuable information about your care wishes.

Resources

- American Bar Association • 800-285-2221 • www.americanbar.org
- Compassion and Choices • 800-247-7421 • www.compassionandchoices.org
- Family Caregiver Alliance • 800-445-8106 • info@caregiver.org • www.caregiver.org
- National Academy of Elder Law Attorneys • 520-881-4005 • www.naela.org
- National Hospice and Palliative Care Organization Caring Info • 800-658-8898 • www.caringinfo.org
- National Institute on Aging Advance Care Planning • www.nia.nih.gov
- National POLST Paradigm • 202-780-8352 • info@polst.org • www.polst.org
- State medical societies in the U.S. by state • www.emedevents.com • www.thedoctors.com
- Values History from University of New Mexico Institute for Ethics • 505-272-4566
• hsc-ethics@salud.unm.edu • <https://hscethics.unm.edu/directives/values.html>

Compassionate Allowances

Source: Social Security Administration website

Compassionate Allowances (CAL) are a way to quickly identify diseases and other medical conditions that, by definition, meet Social Security's standards for disability benefits. PSP, CBD, MSA, and other brain disorders are on the list of conditions allowable for Compassionate Allowances. The CAL program helps reduce waiting time for a disability determination for individuals.

The Compassionate Allowances program identifies claims where the applicant's disease or condition clearly meets Social Security's statutory standard for disability. By incorporating cutting-edge technology, the agency can easily identify potential Compassionate Allowances. The Social Security Administration (SSA) uses the same rules to evaluate CAL conditions when evaluating both Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) programs.

SSA receives information from the public, comments from the Social Security and Disability Determination Service communities, counsel from medical and scientific experts, research with the National Institutes of Health (NIH), and information from past public outreach hearings regarding potential CAL conditions. For more information on how to submit a potential CAL condition to the Social Security Administration, go to their website at www.ssa.gov/compassionateallowances or call 800-772-1213.

The Social Worker's Role

Diane Breslow, MSW, LCSW

Living with a chronic, progressive illness like PSP, MSA, or CBD can pose many different and changing challenges over a long period of time. Each of the diseases is "family disease." While one person may have the diagnosis, the whole family experiences the effects. Social workers play a key role in helping people with these diseases and their families to deal with those challenges and to navigate the healthcare system, community services, and the many feelings and situations encountered.

Because symptoms and abilities change over the years, many families find that what worked or helped at one point may not be the best option at another time. Whether you are seeking advice in managing the impact of disease progression or need help finding resources (such as a support group or new housing possibilities), talking with a social worker can be an important step in helping explore new options and creative ways of living well.

Why Social Work?

Social workers offer an important skill set and mindset. Social workers subscribe to the biopsychosocial model of assessment and care. That is, they are trained in the theory that individuals and families are a composite of complex physical (biological), emotional (psychological), family, and social/cultural aspects, all of which combine to play a role in behavior and relationships. Because the problems of neurodegenerative disease impact people in so many ways, disease management requires a comprehensive team approach:

one that includes social workers and other allied healthcare professionals (physical therapist, speech therapist, occupational therapist) who can intervene on all levels. Some social workers, as well as rehabilitation professionals, specialize in these diseases and their unique challenges.

Ideally, social workers can provide the best care in an ongoing relationship with clients in which trust can be built over time. Regular visits afford the social worker the opportunity to understand the client's perspective, strengths, and unique challenges—and to work with clients to develop a mutually agreed upon treatment plan. Sometimes clients meet with a social worker only once—for a specific issue, for information about a service, or at a point of transition or crisis. Some patients and their families also talk with social workers at periodic intervals, as specific needs emerge during the course of the disease.

Social workers aim to understand each person and family's unique situation and goals. Therefore, social work intervention is not a one-size-fits-all approach. Every case is viewed and treated individually. What one couple or family finds helpful may be very different for another couple. For example, one couple wants help to remain in their own home, while another couple wants to understand assisted living options and locating an appropriate residential community. Furthermore, it is fairly common for one person in a couple to see a situation differently from the other, or for adult children to hold different views from one another. A woman with PSP may believe she can still travel the world, while the husband/carepartner feels quite reluctant about this. Or one adult child views Dad as “not changed at all,” while the other adult child treats Dad as helpless. These kinds of different perspectives can create new conflict or cause old conflicts to re-emerge. Social workers are trained, experienced, and successful at dealing with these kinds of issues.

Reasons to See a Clinical Social Worker

- To better understand the disease and to discuss reactions to receiving the diagnosis
- To talk about when and how to share the diagnosis with family members and friends, or at the workplace
- To find new ways to cope with feelings such as sadness, depression, anger, fear, or frustration
- To develop new attitudes and habits of flexibility, persistence, and adaptation, with a focus not on cure but rather on living the best life possible and creating new meaning
- To plan for the future, including advance directives, insurance issues, home care, and housing options
- To express and deal with losses—physical, emotional, and social
- To adapt to changes in family roles and dynamics, such as taking on the role of carepartner
- To find ways to build or maintain good communication with a carepartner and other family members
- To deal with different kinds of reactions and myths or misinformation of family, friends, and the general public
- To learn about and access resources: community services, programs, classes, and support groups

Resources a Social Worker Might Suggest

- Associations like CurePSP
- Home safety evaluation
- Workplace accommodation
- Driver safety evaluation
- Social Security Disability
- Legal assistance
- Exercise classes and videos

MANAGING CARE (continued)

- Transportation
- Support groups
- Caregiver support
- In-home help
- Respite
- Palliative or hospice evaluation

The Social Worker's Clinical Roles

- Individual and family counseling, both short- and long-term
- Facilitating support groups for diagnosed individuals as well as caregivers and loved ones
- Providing resources and disease education to patients, families, and other healthcare workers involved in the patient's care
- Linking patients and families with appropriate community services
- Care management or case coordination with patient's other healthcare providers
- Peer-to-peer (one-to-one) pairings of patients with other patients, or caregivers with other caregivers
- Telephone consultation to patients and families
- Advocate for multidisciplinary interventions, including physical therapy, speech and swallow therapy, and occupational therapy

Facts about Social Work

- Social work degrees are awarded at the bachelor's, master's, and doctoral levels. Most licensed social workers have a Master's in Social Work (MSW), a state requirement.
- All 50 states in the U.S. license social workers. However, many people without licenses call themselves social workers. The best way to get clarity is to ask the professional you are seeing if they are a licensed social worker. "Licensed social worker" is a regulated title; "social worker" is not.
- LMSW, LCSW, LGSW, and LSW are typical initials you might see after a licensed social worker's name. The meaning of these titles varies among states.
- The National Association of Social Workers (NASW) is the main professional social work governing body.
- In many settings, licensed clinical social work services are reimbursable.
- Some healthcare settings where you can find social workers:
 - Medical institutions and rehabilitation centers
 - Adult day programs
 - Home health agencies
 - Assisted living and skilled nursing facilities
 - Veteran's Administration (VA) centers
 - Palliative and hospice care
 - Private practice

Understanding Levels of Home- and Community-Based Services and Residential Care

Diane Breslow, MSW, LCSW

CurePSP is committed to providing its constituents—patients, families, caregivers, and healthcare providers—with up-to-date educational information about topics relevant to living with PSP, CBD, MSA, and other neurodegenerative diseases.

Among the ever-increasing population of older and disabled adults and their caregivers and family members, confusion and misunderstanding abound with regards to the broad spectrum of available choices for home- and community-based services, residential facilities, long-term care, and rehabilitation. Part of the reason for this confusion is that, throughout the 50 states, a lack of consistency exists in terminology, regulations, licensing, on-site services, costs (up-front and add-ons), amenities, and more.

This article will help you understand the spectrum of services and care options for adults with physical impairments or chronic disease. You will become aware of questions to ask when searching for a type of care or care facility.

Each of the services and care levels discussed are potentially appropriate for people with PSP and related diseases. That said, it is most important and acceptable for family caregivers to inquire as to a staff's experience with prime of life neurodegenerative disorders like PSP. Family members can and should make providers aware of the symptoms and needs of these patients, and offer to ascertain educational materials, speakers, and in-service training for staffs.

Adult Day Services (also called Older Adult Day Programs, or Adult Day Care Centers)

Adult day services are community-based, daytime group programs for cognitively or functionally limited adults who require supervision, socialization, structure, and some personal assistance. The programs are provided in a safe and secure setting, sometimes in stand-alone buildings and sometimes within hospital campuses or continuing care retirement communities (CCRCs).

Adult day centers feature exercise, socialization, and recreational activities.

Other possible components are:

- Transportation
- Health-related services, such as medication reminders, incontinence care, nurse oversight
- Meal and snack
- Social work services, such as counseling, information, referrals, and care coordination

Features and fees vary from program to program, and state to state. It is important to ask specific questions about what is and is not included in any one center.

Note: In addition to the benefits to participants, adult day programs afford family caregivers much-needed respite from the demands of caregiving full-time for someone who needs constant supervision.

MANAGING CARE (continued)

Medical/Rehabilitation Services: Physical, Occupational, and Speech Therapies

Even with a neurodegenerative disorder such as PSP, rehabilitation therapies can offer helpful safety instructions and can help re-stabilize an individual's functioning. The skilled rehabilitation therapies of physical therapy, occupational therapy, and speech therapy are provided in multiple different settings:

Inpatient rehabilitation takes place in either a dedicated rehabilitation center or institute, or in a rehabilitation unit of long-term care facilities or hospitals. To qualify for admission to an inpatient rehab center, one must meet specific criteria related to one's ability to participate in and benefit from daily, intensive, multiple therapy sessions.

Day rehabilitation treatment centers offer community-based treatment in an outpatient setting or clinic. Some day rehab programs are housed within a larger rehabilitation institute. The patient must meet specific criteria related to ability to undertake several hours of skilled therapy throughout the day.

Outpatient centers provide therapy in a community clinic, hospital, or agency. Therefore, as with day rehabilitation, the person must be able to leave their home for therapy. Unlike day rehabilitation, outpatient therapy consists of a one-hour session at a time of physical, speech, or occupational therapy.

Home health care: If a patient is deemed to be home-bound, then skilled care or rehabilitation therapies along with visits from a registered nurse, can take place in one's home. During the time that a case is open for home rehab, the patient is also eligible to receive a bath aide. However, once the course of rehabilitation ends, so too does the bath service.

Medicare or insurance covers skilled rehabilitation therapies, subject to initial evaluation and periodic re-evaluations.

Non-Medical or Personal In-Home Care

Non-medical or personal home care refers to personal care with activities of daily living, such as bathing, grooming, and dressing. In-home care providers are also called companions, personal aides, home health aides, homemakers, or personal caregivers. These kinds of home-care providers work for themselves (privately) or are employees of an agency that takes responsibility for setting fees, making caregiving assignments, insuring and bonding the caregivers, and training them.

Home health agencies offer caregiving services in any of three ways:

1. By task, such as bathing assistance
2. By blocks of time or shifts, such as 4 hours or 8 hours
3. Live-in

For the most part, personal care is a private expense. Medicare or health insurance does not cover personal care. However, it may be covered by one's long-term care insurance policy. In addition, some states, through their local Area Agencies on Aging, offer subsidized, and usually "capped," personal care services for individuals with limited financial means.

Independent Living: Senior Apartments, Active Senior Communities, and Retirement Homes

Independent living is a broad term that encompasses senior apartments, active senior communities, and retirement homes. These types of buildings are age-restricted (for example, 55 and over, or 65 and over) and are not licensed to provide personal care or nursing services. Basic services include a certain number of meals (per day, week, or month, depending on the particular facility), housekeeping or laundry (this could

mean laundry or only linens, or also personal clothing), social activities, well-being checks, and transportation to doctors and outings. For an additional cost, personal care assistance can be purchased, either on-site or from an outside home care company (see above). Some independent living buildings are federally or state subsidized; however, most are private-pay. Families need to ask detailed, specific questions about what features and services are and are not included in the cost of any one independent living facility. Costs and inclusions can vary greatly.

Assisted Living

Assisted living refers to an entire building, a specified unit of a building, or a part of a continuing care retirement community (CCRC) that is licensed to provide 24-hour-a-day personal care for activities of daily living, in addition to offering the basic services of independent living (see above): meals, housekeeping, and social programs. However, the assisted living license—and its definition of which care services or how many—can differ from state-to-state. *Assisted living is the fastest-growing type of residential care with the most discrepancy in definition.* Again, it is crucial for prospective residents to ask very specific questions as to the type of care—and caregivers—offered in a particular building. In general, assisted living caregivers are trained, certified aides who assist with daily tasks—for example: bathing, dressing, escort to meals, medication setup and dispensing, and routine checks on residents. The role of a registered nurse (RN) may vary from facility to facility. At the least, the RN should be the one who sets up and stores a person’s medications. The aide may be the person who delivers the medicines to the resident. Even the definition of the term “delivers” regarding medication may vary. “Deliver” could mean: to drop off the medication in the person’s room; to pour it into the hand of the resident, who then takes the medicine; or to administer the medicine to the person. Assisted living facilities may also supply transportation to and from medical appointments, errands, and group outings. Some facilities may offer rehabilitation therapies, hospice care, and specialized care for different disorders (such as dementia). If the facility offers rehab or hospice, the same regulations for physician referral, evaluation, and insurance or Medicare coverage apply as when someone is living in their own home. In addition, residents are free to choose their own rehabilitation provider, even if the facility houses its own or another company on-site.

Supportive Living

Supportive living refers to state-funded facilities—in some but not all states—for seniors who need assistance with daily living, as in assisted living (above). Individuals need to check with their own state’s Area Agency on Aging or a social worker familiar with community resources.

Skilled Nursing Facilities (SNFs) or Nursing Homes

Skilled nursing facilities are institutions that are licensed and regulated by state and federal governments to provide room and board, daily personal care, supervision, medical care and oversight, and 24-hour-a-day care from registered nurses (RNs) and certified nursing assistants (CNAs). Physicians (MDs) serve as medical directors of skilled nursing facilities. Many, if not most, nursing homes are certified for Medicare and/or Medicaid coverage for a certain number of beds (residents) per facility. Medicare certification allows for short-term rehabilitation stays only. Medicare and supplemental insurance policies usually cover 100 days of nursing home care that results from a hospitalization and meets the criteria for rehabilitation therapies. For those people who are not on Medicaid or the short-term allowance of Medicare, skilled care is a private expense and/or may be covered by a long-term care insurance policy.

MANAGING CARE (continued)

Skilled nursing facilities are composed of various types of care:

- Custodial or Basic Care: Assistance with personal care (activities of daily living such as bathing, dressing, or toileting), ambulation, safety, supervision, and medication dispensing
- Skilled Care: Treatments or procedures, such as wound care; intravenous medications or feedings; or managing of machinery, such as respirator or ventilator
- Sub-Acute Care: Short-term rehabilitation stay (discussed above) to provide rehabilitation from an acute illness, injury, or exacerbation of a disease process
- Respite Care: Short-term or trial stays in the facility; or “vacation stays” while the family caregiver takes a break. Respite is a private-pay service. Additionally, some states and private or non-profit foundations may offer respite funds.

Continuing Care Retirement Communities (CCRCs)

Continuing care retirement communities (CCRCs) are residential campuses comprised of a number of buildings, offering a range of care options, all on the same grounds. Within such a community there might be independent living, assisted living, and skilled nursing. However, not all CCRCs provide all levels of care. Most CCRCs require an upfront investment of some amount as well as monthly payments. Specifics differ from community to community, so it is important to ask questions and do comparison shopping.

Special Care Units (SCUs) and Memory Care Units (MCUs)

Some states license, and thereby recognize the designation of, special units that exist within facilities that are already licensed to give care. Examples of specialty licenses are memory care assisted living and memory care skilled nursing. If facilities advertise as memory care and are located in states that assign such licenses, then the facility must have that license.

Patient Medical Information

No matter where your loved ones live or attend programs such as those described here, they should always keep with them, and in a specified location in their living space, written medical information in the event of an emergency. This document is often referred to as a “vial of life.” It should contain the following information:

- Date updated
- Name, address, phone number
- Medications, dosages, frequency or times
- Drug allergies
- Medical conditions
- Surgeries (including year)
- Blood type
- Allergies
- Inoculations
- Physicians (primary care, movement disorders neurologist, and any other key doctors) and their phone numbers
- Durable Power of Attorney for Health Care
- Emergency contacts

Because information can change, you should regularly review and update the document. In case of emergency, carepartners should keep a copy with them and place another copy in the home—in a visible spot, such as taped to the refrigerator.

Resources

- AARP • www.aarp.org
- Administration for Community Living • www.acl.gov
- Aging Life Care Association • www.aginglifecare.org
- Eldercare Locator • 800-677-1116 • www.eldercare.acl.gov
- Medicare • 800-MEDICARE • www.medicare.gov
- Medicare Nursing Home Compare • www.medicare.gov/nursinghomecompare/
- Medicare & You Official Government Handbook • www.medicare.gov/medicare-and-you, or obtain your print copy by calling 800-MEDICARE
- National Center for Assisted Living (NCAL) of the American Health Care Association • 202-842-4444 • www.ahcancal.org
- National Institute on Aging • www.nia.nih.gov; Long-Term Care • www.nia.nih.gov/health/caregiving/long-term-care
- Social Security Administration • 800-772-1213 • www.ssa.gov
- Veteran's Administration Helpline • 800-827-1000 • www.va.gov
- Vial of Life: This nonprofit provides materials for allowing first responders access to relevant medical data in your home • www.vialoflife.com

Caregiver Associations

- Family Caregiver Alliance • www.caregiver.org
- National Alliance for Caregiving • 301-718-8444 • www.caregiving.org
- National Family Caregivers Association • 800-896-3650 • www.nfcacares.org

CurePSP Support Groups

Wendy M. Resnick, RN, MS, CS

What is a CurePSP support group?

A CurePSP support group is a voluntary gathering of people who share common experiences, situations, or problems related to living with a prime of life disease such as PSP, CBD, or MSA. Group members offer each other emotional and practical support and reduce the sense of isolation that is associated with rare brain diseases. The purpose of the support group is to help people with PSP and other prime of life diseases to develop new and existing methods of coping with the problems associated with these diseases.

Who attends CurePSP support group meetings?

A very diverse group of people attends these groups. Brain diseases are not specific to any race, gender, socioeconomic group, or religious background. As is true of most support groups, there is a common bond: people whose lives are significantly affected by PSP and related brain disorders. Because of the mature discussions that take place during the meetings, the appropriate age for people attending the meetings is 18 years and older.

The following types of individuals can be involved in attending support group meetings. Many groups involve both the person with the disease and family members or significant others, since sharing mutual concerns and perspectives can often be especially helpful. However, some group meetings are just for family members or patients separately, creating a welcome haven for individuals to share their personal point of view as to how they experience dealing with their loved ones.

Professionals may be invited to attend support groups—for example, nurses, social workers, physicians, or anyone who serves as a paid helper who provides assistance to people with these diseases and their families.

What happens at meetings?

The meetings provide the opportunity to share information and mutual support. Meetings might consist of group sharing without a specific agenda, a planned program with literature provided, or an open discussion surrounding a topic of interest. Whatever the format for a particular meeting, there is always an opportunity for personal sharing.

What do people learn?

Information about PSP and related neurodegenerative brain diseases:

- What are typical symptoms?
- What constitutes a thorough evaluation and diagnosis?
- How do these diseases vary from person to person?
- What can be expected as the disease progresses?
- What treatment options and clinical trials exist?

Information about available resources in the community:

- Where do I go for help?
- What disability benefits are available and how do I apply?
- What options are available for respite care?
- What if I have to admit my loved one to a nursing home?

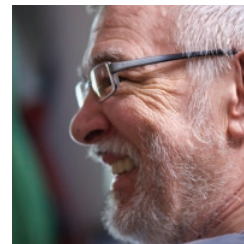
Information about identifying methods of coping:

- What if there is no help at times?
- What if there is family conflict, or lack of understanding on the part of well-meaning relatives and friends?
- How do family members deal with the possibility of needing to place a loved one into a nursing home?

Feelings of anger, fear, guilt, frustration, and grief interfere with decision-making. Talking about feelings with others helps to sort things out. Through sharing together, people help each other appreciate the range of responses to situations, their growing knowledge of the disease, and their ability to make use of practical coping strategies.

How do I find a CurePSP support group?

Please go to our website www.psp.org/ineedsupport/supportgroups/ where you will find listings. If you don't have access to the Internet, please call Joanna Teters at 347-294-2871.



When to Stop Driving: The Hard Conversation

Lissa Robins Kapust, MSW, LICSW

PSP and Driving Safety

Driving is a complex skill that demands high-level cognitive and physical abilities. Many view driving as a marker of independence. However, PSP will likely jeopardize safe driving at some point in the illness. Those with PSP and their family members will need to monitor the course of the illness and the impact of symptoms on driving safety. It is important to recognize that no two patients with PSP will progress in the same way; each situation is different. But because driving can impact personal and public safety, it is an issue that bears careful monitoring and in most people with PSP, is impaired early in the course of the illness, typically after only two or three years, often sooner. One way to monitor driving is for family members to ride as passengers with the person who has PSP. It can be a red flag when family members no longer allow the person with PSP to drive with others, especially with children.

PSP is an illness that affects motor and cognitive domains. Motor symptoms such as stiffness and slowness may limit the speed and accuracy of manipulating and switching between the gas pedal and the brake. For some people, eye movement problems lead to an inability to scan the environment actively and accurately. This may be further exacerbated by neck stiffness, which limits the ability to turn the head for compensatory scanning. The ability to judge distances is impaired early on in PSP.

As important as the motor skills necessary for safe driving are cognitive and emotional factors. PSP can decrease speed of processing information, which is important in all aspects of driving and decision-making. This is especially true when unexpected situations arise and a decision needs to be made quickly. Poor sleep, a common issue in PSP, can contribute to problems maintaining attention. Judgment errors add to the risk of safe driving. Other contributing behavioral changes—such as impulsivity, depression, and anxiety—also negatively impact driving safety.

Our society values independence and the ability to drive. But when a person becomes a danger to themselves or others, it is time to consider giving up this privilege. Different physical and cognitive conditions may impair driving. It is advisable to ask physicians about conditions or medications that may affect driving ability. It is important for families to observe driving behavior over time.

Some of the warning signs of driving problems include:

- Hitting curbs
- Dents or scrapes on the car or garage
- Getting lost
- Diminished insight and judgment
- Impulsive behavior
- Driving too slowly for the conditions
- Incorrect signaling
- Making turns too widely or sharply (inability to judge a turn's radius)
- Changing lanes without looking
- Making wrong judgments, causing other drivers to constantly honk or take evasive action

- Stopping at green lights instead of red lights
- Not understanding signage
- Getting confused at freeway entrances and merges
- Driving the wrong way on a one-way street

There is no right way to resolve the driving difficulty issue. The responses of individual family members may vary. Those involved with the care of the driver need to remain focused on the self-respect of their loved one and the safety of others on the roadways. Understandably, one doesn't want to prematurely end driving, but waiting too long can jeopardize safety and result in serious injury or death.

What to Do

1. Begin discussions and planning early; anticipate with the patient that there may be a time when they can no longer drive. When possible, involve the driver in these conversations. Open and early communication can help avoid a crisis later. Many carepartners permit their loved ones to drive longer than they know they should, causing carepartner anxiety and fear of putting others at risk.
2. When it is time to give up the keys, explain everything to your loved one and do not become critical of them. "Medicalizing" the problem can help. For example, let your loved one know that PSP results in symptoms that interfere with safe driving. You are there to support the person and tell them you understand their feelings.
3. Never leave the keys out where they can be found.
4. Assure your loved one that they can depend on you to meet their transportation needs.

Determining Driving Safety

It is sometimes hard to know the degree to which illness impacts safe driving. If the impaired driver resists driving cessation, talk to the neurologist or family doctor. Based on the office visit and the patient's history of crashes, the physician may believe that they can strongly recommend the patient stop driving. However, sometimes it is hard to know from the office visit whether the patient is still safe to drive, since driving is an overlearned skill (like riding a bike). Each state differs in its procedures, but you or the neurologist may choose to contact your Division of Motor Vehicles and supply the DMV with a Driver Medical Evaluation form. In some states, the driver will then be notified of the need for a formal driving assessment. Another good option is to check to see if driving safety can be assessed through a nearby rehabilitation hospital or another hospital offering this service. Your physician can order such an evaluation. These formal assessments are valuable since the emotionally-charged decision about driving is turned over to skilled professionals who can render an objective opinion. These assessments, often done by an occupational therapist, measure key cognitive functions linked to driving safety, as well as visual and physical functions related to driving. The most comprehensive programs also include an on-road test, most often conducted in the car of a certified driving instructor. If patients do well with this assessment, they and the family can be reassured. Often, follow-up testing is necessary. The guidelines of the American Academy of Neurology suggest six-month follow-up for anyone with a progressive neurological condition.

For information on physical and cognitive impairments and driving, contact your local DMV and ask for the Regional Driver Safety Office. Explain the situation and ask about resources.

MANAGING CARE (continued)

Conclusion

Having the discussion about driving safety is difficult. Driving cessation can be viewed as a sign that one is sick, with the need for major lifestyle changes. Sometimes the person has insight into driving difficulties and can participate in helping make the decision about when to stop driving. But often it is more challenging. Driving alternatives—and in some cases, a move—can help, but, as a non-driver, the spontaneity of going out for an ice cream on a hot July evening may not be possible. Hopefully, with thoughtful discussion, the person with PSP will adjust and the need for more authoritarian measures will not be needed (for example: reporting to the DMV, or removing or disabling the car).

Despite resistance to ending driving, some individuals are actually relieved to stop driving. They may have been in some very anxiety-provoking situations on the road, and they may not have shared this information with family.

In any case, work with the person with PSP to define themselves as much more than a driver—rather, as a person with many strengths. Professional counselors can provide additional help for those experiencing significant mood changes as a result of driving cessation. The family can highlight for the affected individual other times in their life when they have adjusted to change with strength and resilience. Hopefully the individual can draw on these past strengths and family support to manage the transition to no longer driving.

Understanding Palliative and Hospice Care

Diane Breslow, MSW, LCSW

CurePSP is committed to providing its constituents—patients, families, caregivers, and healthcare providers—with up-to-date educational information about topics relevant to living with PSP, CBD, and MSA.

The terms *palliative care*, *hospice care*, *end-of-life care*, *comfort care*, and *supportive care* are widely misunderstood and often used interchangeably. They also may conjure fear, stigma, and myth.

One of the most common misconceptions is that palliative care and hospice care mean “giving up.”

This article will help you understand the care options defined as palliative care and hospice care. In addition, you will find a list of available resources to assist you in making informed decisions about enlisting palliative or hospice services.

Comfort care is the umbrella term for patient care that is focused on symptom control, pain relief, and quality of life. Comfort care includes supportive care to family members by explaining the care plan, responding to questions and concerns, and providing emotional comfort.

Myths and Facts

Myth: Palliative care and hospice care are the same.

Fact: Palliative care and hospice care do not mean the same thing. This section, and the various agencies listed in the Resources section below, can help you understand the differences between palliative and hospice care.

Myth: Palliative care starts at the time of “terminal” diagnosis.

Fact: Palliative care can start upon diagnosis of a serious, chronic illness like PSP, CBD, or MSA, or at any time throughout a patient’s disease progression.

Myth: Medicare covers hospice but not palliative care.

Fact: Medicare pays all hospice costs. Depending on your Medicare benefits and medical treatments, Medicare can also pay for palliative care. *It is important that you or your healthcare provider check with your insurance carrier regarding your benefits.*

Myth: Palliative care does not permit medical, rehabilitation, or curative treatment.

Fact: Palliative care allows for symptom relief and also for tests, curative treatments, and therapies for disability. Hospice permits the patient to receive symptom relief (such as blood pressure or pain medications) but does not authorize the patient to receive curative or life-prolonging treatments. In some cases, patients enrolled in hospice may still receive a treatment typically thought of as life-prolonging (such as chemotherapy) when the purpose of that treatment is to bring *comfort*, not to extend life. *Make sure that you, and your physician, understand these distinctions as they apply to your particular case.*

Myth: Palliative care occurs at home, while hospice care is provided in a facility.

Fact: Both palliative and hospice care can be provided wherever a person resides—in their own home, an assisted living facility, or a nursing home. In addition, some hospitals have palliative care teams, while some hospices offer the option of stand-alone hospice facilities. *Talk with your doctor or social worker about the best choice for you.*

Myth: Hospice provides full-time care at the end of life.

Fact: Family members, paid caregivers, or the staff of a facility (assisted living or nursing home) give daily care to patients who are on hospice. The hospice team recommends and sets up a schedule for its staff—the hospice nurse, social worker, chaplain, volunteers, and others—to see the patient. If a person has chosen to die at home, meaning that family and friends are providing the hands-on daily care, hospice team members teach the lay people how to care for the dying person. Someone from the hospice team is always available by phone.

Similarities Between Palliative Care and Hospice Care

BOTH are specialized care for people with serious illnesses.

BOTH require a physician’s order. The order is not for hospice per se; rather, it is for a hospice evaluation. A member of the hospice team—usually a nurse, sometimes the hospice physician—meets with the patient and family to explain hospice and to determine if the patient meets the admission criteria. If the patient and family find out that the patient is eligible, they can then decide whether or not they will take that route. In other words, choosing palliative or hospice care is a step-by-step, joint decision-making process involving hospice, the patient and family, and someone from the patient’s healthcare team—physician, nurse, social worker.

MANAGING CARE (continued)

BOTH palliative care and hospice care are focused on relief from symptoms, including pain and stress. Even on hospice, when a patient is not being treated curatively, they receive medical care that is helpful and contributes to comfort, such as blood pressure medication.

BOTH aim to improve quality of life and dignity for the patient and the family.

BOTH are made up of teams that include a physician, nurse, social worker, nutritionist, and volunteer visitors, and may also include music, art, and massage therapists.

BOTH include the service of helping patients and families do advance care planning.

BOTH palliative care and hospice care recognize dying as part of the normal process of living. Neither palliative nor hospice care hastens or delays death.

BOTH result in decreased hospitalizations and decreased use of unhelpful services, and in the patient and family's higher perceived quality of care and quality of dying (often seen as "not dying in the hospital"). (See research studies by Mitchell et. al., 2007; Teno et. al., 2011).

An Internet perusal of hospice care research identifies numerous references supporting the premise that palliative care and hospice care do not hasten death:

1. *"...hospice enrollment is not significantly associated with shorter survival; for certain terminally ill patients, hospice is associated with longer survival times."*
(*Journal of Pain and Symptom Management*, March 2007)
2. *"...patients with terminal cancer that disenrolled from hospice care had significantly higher rates of hospitalizations...than patients who remained under the care of hospice."*
(*Journal of Clinical Oncology*, October 1, 2010)
3. *Researchers found that patients receiving palliative care reported a higher quality of life through the final course of their illness.*

Differences Between Palliative Care and Hospice Care

When the care begins: Palliative care can begin at any point in a person's disease process and can be provided concurrently with curative treatments. A referral for palliative care is not dependent upon prognosis or life expectancy. In fact, palliative care can help patients understand treatment options over time and throughout their disease.

Hospice care is for people in the final phase of life-limiting illness when life-saving treatment no longer works or is wanted, and the physician believes that the person has six months or less to live if the illness were to run its natural course. The patient who agrees to hospice understands that their illness is not responsive to treatments that intend to slow or cure it. Provided that a proper re-evaluation is conducted and appropriate hospice eligibility criteria are met, hospice services can be renewed beyond the initial six months. Likewise, a person could choose to discontinue hospice care and re-enroll at a later date.

Who provides the care: Palliative care is provided by a healthcare team of doctors, nurses, and other specialists who work with the patient's current treatment team.

Hospice care is provided by a designated hospice multidisciplinary healthcare team of practitioners: nurses, doctors, social workers, spiritual counselors, massage therapists, creative arts therapists, and trained volunteers. In some cases, if the patient has had a palliative care team, those practitioners continue to provide services but in the new role of hospice care. A hospice team member is available by phone 24 hours a day, 7 days a week.

Patients receiving palliative or hospice care can continue to see their primary care physician and other specialists, though insurance coverage may vary; check with your insurance carrier for limitations.

Families' Experiences Associated with High Satisfaction Regarding Hospice Services

(National Hospice and Palliative Care Organization, 2005—based upon 116,974 surveys from 819 hospices; National Institute on Aging, July 2016)

- Family members concurred that the hospice team regularly informed them about their loved one's condition.
- The family felt that the hospice team provided family members with the right amount of emotional support.
- Family members felt that the hospice team provided them with accurate information about the patient's medical treatment.
- Family members could identify one nurse as the team leader in charge of their loved one's care and care plan.

The Take-Away Message

Although similar, palliative care and hospice care are two distinct care options available to people living with chronic illness or disease. In particular, hospices vary widely as to the services, professional staff, and frequency of visits they offer. A referring practitioner cannot (and should not) promise or assure which services a patient and family will receive from a hospice organization. Families need to consult with hospice agencies on an individual basis to ask questions specific to one's own situation. We at CurePSP hope that you will discuss your needs and concerns with your family, your physician(s), and an experienced social worker or nurse, and then interview at least two different palliative care and/or hospice agencies to determine which one is the best fit for you.

Resources

- American Academy of Hospice and Palliative Medicine • info@aahpm.org • www.palliativedoctors.org
- Center to Advance Palliative Care • 212-201-2670 • capc@mssm.edu • www.getpalliativecare.org
- Centers for Medicare & Medicaid Services • 800-633-4227 • www.medicare.gov
• www.medicare.gov/coverage/hospice-care
- Death with Dignity • 503-228-4415 • www.deathwithdignity.org
- Education in Palliative and End-of-Life Care (EPEC) • 312-503-3732 • info@epc.net • www.epc.net
- Eldercare Locator • 800-677-1116 • www.eldercare.acl.gov
- Family Caregiver Alliance—National Center on Caregiving • 800-445-8106 • www.caregiver.org
- Five Wishes • www.fivewishes.org
- Grandfolk • www.grandfolk.com
- Hospice and Palliative Nurses Association • 412-787-9301 • hpna@hpna.org • www.advancingexpertcare.org
- Hospice Association of America—National Association for Home Care and Hospice
• 202-546-4759 • hospice.nahc.org
- Hospice Foundation of America • 800-854-3402 • info@hospicefoundation.org • www.hospicefoundation.org
- National Hospice and Palliative Care Organization • 800-658-8898
• caringinfo@nhpco.org • www.caringinfo.org • www.nhpco.org
- National Institute on Aging Information Center • 800-222-2225 • niaic@nia.nih.gov • www.nia.nih.gov
- U.S. Department of Veterans Affairs • www.va.gov/GERIATRICS/Guide/LongTermCare/Hospice_Care.asp

Caring from a Distance

Susan C. Imke, FNP, GNP-C

Relatives who live far from loved ones coping with chronic neurological illness are often at a loss as to how to be helpful in ways that are both meaningful and practical. It can be tempting for family members at a distance to offer advice that may not be welcome or easily implemented.

Part of my work is facilitating family conferences for the purpose of making elder care decisions for people with PSP and related neurodegenerative disorders. Sometimes, the son or daughter who lives furthest away is the one with the strongest opinion regarding what Mom or Dad needs. This can result in friction with weary or exhausted front-line caregivers.

While relatives not struggling with issues of daily care do have a valuable perspective to share, this objective wisdom must be expressed with great tact and without criticism for family members who live close by and carry the greater responsibility.

All family members need to avoid making rash promises to the person with chronic health problems. Rather than saying, “Of course we’d never put you in a nursing home,” express your empathy for a parent’s preference to live at home, and your willingness to explore alternatives as care needs change.

So, what *can* long-distance relatives do to be helpful, short of moving back home? Perhaps some of the following suggestions from caregivers in support groups around the U.S. will meet needs for your family:

- Agree on a designated day and time to call each week. Do not assume that “no news is good news.” Many older parents keep their own counsel even during tough times, not wanting to bother children who are busy with their own lives. Make the call faithfully. A short call more frequently may be better than an extended telephone visit. You may need to do most of the talking. Share your own family’s activities since you last spoke.
- Try not to over-quiz the elders about health issues; this may put them on the defensive. If you are the son, speak for yourself. Your parents may dearly love their daughter-in-law but are likely to feel grateful to hear from you personally.
- Inquire tactfully whether financial help is needed. Many parents won’t ask for help of a monetary nature, even if living on a fixed income and the rising cost of medication can mean eliminating basic necessities.
- If a regular subsidy is unacceptable, offer something specific.
- Picking up the tab for pads and diapers is useful for the person with incontinence. Paying for a month’s supply of medication that is not covered by insurance can be a great relief.
- Send a creative caregiver package once a month. This might be a flower arrangement, restaurant gift certificate, or a spa basket filled with elegant bath goodies. Even a simple card with an encouraging hand-written message can mean a lot in the midst of a trying day!
- Budget funds for regular visits to see your family. Consider getting your own ride from the airport. The primary caregiver should not have to take care of you, too! If crowded quarters put a strain on everyone, reserve a nearby hotel room. You are not there to be entertained but to provide a listening ear and a helping hand.

- Educate yourself about the medications your loved one is using, and if helpful, report problems and changes to their physicians. Inquire about the health of the “well” parent. Is your mom’s mammogram overdue? Does your dad neglect his own medical checkup because he’s preoccupied with taking care of his wife? Ask your parents to schedule an appointment with the neurologist for a time when you can accompany them. The doctor will benefit from hearing your observations, and you will learn much about your parents’ communication style and be able to reinforce the medical instructions afterwards.
- Once or twice a year, offer and follow through with a 3- to 5-day respite stay for the primary caregiver. Arrive a day or two prior to the caregiver’s leave of absence so that you can learn necessary skills to help your care recipient. If filling in personally is not possible, offer to pay for a respite stay in an extended care facility. Your family may be saving for a rainy day when it’s pouring outside!
- If your parents are able to travel, invite them to visit you. For some older couples who are living with chronic neurological disease, it is easier to travel and be a guest in your home than to host family visits at their home. An added benefit when parents are visiting you is that relatives back home get a welcome break from their usual caregiving responsibilities.
- When the time comes, speak up as the out-of-towner with less caregiving burden, to affirm the difficult decision to place your loved one in a residential care facility. It is a mistake to allow worries about cash flow, sibling rivalry, or dwindling inheritances get in the way of doing what is best for the key players whose lives are most affected.

Respite Care

Diane Breslow, MSW, LCSW

What is respite?

Caregiving is a tough job with long hours. To maintain your health and sanity and provide the best care for your loved one, respite is essential. Respite refers to short-term, temporary care provided to people with disabilities so that their families can take a break from the daily routine of caregiving. Respite services may sometimes involve overnight care for an extended period of time. Respite is an insurance policy against overtaxing yourself so that you can continue to provide quality care for the person with PSP, CBD, or MSA. Respite care enables families to take vacations or even just a few hours of time off. Respite is often referred to as “a gift of time.”

What kinds of services are provided, and where?

Services are provided in many ways depending on the provider, the needs of the family, and available funds. The two primary categories of respite include in-home and out-of-home services. The following are typical services provided in each category.

MANAGING CARE (continued)

In-Home Respite

Informal, Personal Arrangements: This refers to a situation in which a family caregiver prepares and trains a couple of friends or other family members to fill in. Every family caregiver should have a back-up plan, and more than one option, in case someone is not available.

Home-Based Services: A trained, licensed, insured, and bonded employee of a private or state agency comes to the home. Ideally, service is available 24 hours a day, 365 days a year. Even if you do not employ regular home care, you can use a home help agency for the purpose of respite.

Companion Services: These services are provided by individuals who are trained in caring for adults and children with disabilities. This type of service is sometimes provided through a non-profit or service organization. In many cities across the country, Area Agencies offer respite care to the at-home spousal or family caregiver.

Trainer Services: A caregiver may be selected by the family or may be a family member. This individual receives training from a respite program. These caregivers may be paid or unpaid.

Out-of-Home Respite

Family Care Homes: Respite is provided in the provider's home. The home and the individual providing care should be licensed under state regulations.

Respite Adult Day Care: As discussed in the section "Understanding Levels of Home- and Community-Based Services and Residential Care," community-based adult day programs provide all-day, structured programming to adults with physical and cognitive impairments. While enhancing patients' socialization and keeping patients safe, these adult day centers also offer family caregivers a respite from the demands of full-time caregiving for someone who needs constant supervision.

Residential Facilities: Most long-term residential facilities—independent living, assisted living, and nursing homes—offer short-term, overnight respite stays.

How do family caregivers benefit from respite services?

More than providing direct relief, the benefits of respite care can also include:

- **Relaxation:** Families can relax, gain peace of mind, and renew their humor and energy.
- **Enjoyment:** Families can enjoy favorite pastimes and pursue new activities.
- **Stability:** Respite can improve the family's ability to cope with daily responsibilities and maintain stability during crisis.
- **Preservation:** Respite helps preserve the family unit and lessens the pressures that might lead to institutionalization, divorce, neglect, or abuse.
- **Involvement:** Families can become involved in community activities and be less isolated.
- **Time off:** Couples or families can take a needed vacation or merely spend time together and time alone.
- **Enrichment:** Respite makes it possible for family members to establish individual identities and enrich their own personal growth and development.

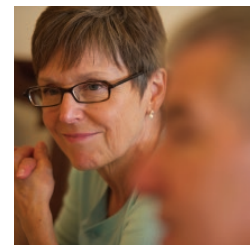
Things to Consider When Seeking Respite Services in Your Community

- What kinds of services do I need? For example, long-term, short-term, or both, and why?
- Do I prefer services in my home or at an outside setting?
- Do I want to use an individual or an agency?
- Does the agency provide the type of services I need?
- What is the cost of services? How is payment arranged?
- What are the training and experience of the care providers? Will they need—and accept—additional disease-specific, hands-on instruction and education to meet the patient’s needs?
- How, and by whom, are the care providers supervised?
- Does the program maintain up-to-date information about medical and other needs? Is there a written care plan?
- What procedures does the program have for emergencies?
- Can family members meet and interview the people who care for the patient?
- How far ahead of time do services need to be arranged?
- Are families limited to a certain number of hours of service?

If Service is Provided Out-of-Home

- What is a typical daily schedule?
- How are the meals handled?
- Is the program able to meet the individual’s specific needs for physical assistance, medication, food preparation, and the like?
- Does the program offer transportation?
- What is the client-staff ratio?

Many family caregivers have a difficult time reaching out for help and relief from their caregiving responsibilities. Sometimes, a respite trial can be a good way to experience what it is like to let someone else care for your loved one. You can gain knowledge and clarity by thinking through and discussing your questions with others. Hopefully, your experience with respite meets the dual goals of helping you—the carepartner—to feel revived and refreshed while at the same time taking care of your loved one’s needs.



PART TWO

Being A Carepartner



Keeping Families Strong

Ileen McFarland
Diane Breslow, MSW, LCSW

PSP, CBD, and MSA are very challenging diseases that have significant impact on patients as well as their families. It is important to respect and accept that each person in the family may have different reactions and coping styles. Nonetheless, family members will benefit from exploring how each of you can grow stronger while traversing this difficult journey.

Family Roles

You may notice that, once a diagnosis is given, family members assume different positions or roles in the family system. While not an exhaustive or rigid list, the following role descriptions may help you gain a better understanding of your family dynamics and feel less alone.

The Leader: Often, one family member steps up to become the Leader. They take control of the situation. They obtain a wealth of disease information. They initiate actions such as making medical appointments. They appoint themselves in charge of communication with other family members. And they are the one to offer support. Being actively engaged is one way that the family “leader” deals with emotions.

However, the negative or flip side to this leadership role is that the Leader may become overburdened and burned out. Wanting to appear strong, they may have difficulty expressing emotions or asking for help, lest other family members view them as slacking in this role. Sometimes, the Leader can grow to resent those family members who are less involved than they are. Even if they do not verbalize these feelings, they will likely express them in actions.

The Supporter: Supporters are more than willing to help, but they lay out clear boundaries. They are most comfortable taking on specific tasks that have a defined beginning and end—for example, accompanying Dad to a doctor’s appointment. The Supporter may be reluctant to provide hands-on help and may seem distant from other family members. The Supporter may openly express feelings of anger or resentment, which can be particularly hard for Leaders, who view themselves as taking on the lion’s share of responsibility.

The other side of the Supporter’s role can be a sense of feeling excluded and uninformed about the patient’s disease and treatment. Knowing that their involvement is “only” task-related, the Supporter may feel that they do not have the right to ask for more information. Because they have set limits on what they will and will not do, they may also feel less valued, or de-value themselves. If they get a sense that other family members resent their boundaries, they may feel guilty or angry.

The Bystander: The Bystander pulls away during the course of the disease. They may reduce overall communication with the family and may avoid direct interaction with the person who is ill. They are very unlikely to take on caregiving tasks. Their lack of involvement often makes other family members feel taken advantage of, disappointed, frustrated, or angry. The bystander may have very understandable reasons for their distance.

Nonetheless, they are missing out on the rewards of caregiving: feeling helpful, feeling closer to the ill person or others in the family, or finding new meaning or purpose in life. Bystanders may feel helpless or ashamed about their role. They may become depressed, which, because of their self-imposed isolation, other family members may not recognize.

BEING A CAREPARTNER

The Only One: In certain cases, only one person in the family is responsible for the care of the patient. Yet, at some point, every caregiver will need assistance with the patient's day-to-day care, not to mention back-up plans for emergency situations. The enormity of being the Only One clearly dictates the need for additional support. Over time, the Only One may become socially isolated and may compromise their own physical and mental health in favor of the patient's well-being. It is important for other family members, friends, clergy, and community members to reach out to the Only One in an effort to help them to develop a support network.

Characteristics of Strong Families

Many factors contribute to and characterize family strength. The first is a **feeling of safety and trust** within a family. Strong families exhibit a respect for, and an encouragement of, sharing thoughts and feelings with each other, even in the face of disagreement, conflict, and intense emotions. Greater closeness and strength ensue when family members behave respectfully, listen openly to one another, and try to understand different points of view.

Family history and tradition can also foster family strength and a sense of togetherness. If families can maintain their customs and observances, even during illness, they have a better chance of staying close, keeping their family traditions alive, and building more memories.

Another characteristic of a strong family is the **willingness of individuals to help one another and to share responsibilities**. Most likely, each family member, whether near or far, has a special ability or talent that they can offer. For example, one individual may be more adept with financial records and bookkeeping. Another family member may enjoy shopping or running errands. Another may accompany the patient to doctor or therapy appointments. There are plenty of tasks to be distributed and shared.

Resilience is another component of strong and healthy families. "Resilience" comes from the Latin root meaning "leap back from" or rebound. Resilience is the capacity not only to withstand hardship but also to spring forward from it, often with a newfound sense of courage, determination, and inner resources. Resilient people can adapt to change, find new and creative solutions to complex problems, and accept what has become the "new normal." As the diseases of PSP, CBD, and MSA change and worsen over time, the "new normal" also changes. Families are called upon to be flexible, cooperative, tolerant, accommodating, and willing to compromise. No one can be this way all of the time. Yet, even while feeling conflicted or overwhelmed, strong families strive for this ideal of resilience and flexibility.

Open boundaries: Strong families let others in. People are not afraid or ashamed to ask for help, whether physical or emotional, in a healthy family. Open-boundary families welcome outside support and viewpoints.

Practical Pointers for Building a Strong(er) Family

Although the person with the diagnosis is usually the family's central concern, family members also need to focus on themselves and how they can best work together. To that end, here are some pointers.

Realize that there are stages of adapting to living with chronic illness. Be patient with yourselves and the process. The stages are:

1. Disbelief, or rejection of the diagnosis
2. Recognition: The reality is hitting. Now what?
3. Reorganization: Bringing others into the circle of people who know and may be able to provide support
4. Resolution: The disease is real. What does it, or what will it, require? How will we build our network of support and find resilience and hope?

Share positive emotions. Openly express love, affection, and appreciation of one another.

Accept each other. Recognize the humanness in one another; respect each person's efforts to cope under such difficult circumstances.

Define roles. As a family, make decisions as to who will take on a particular task. Recognize that roles will need to change over time.

Communicate. Set up routines to stay in touch; attempt to resolve conflicts directly and quickly.

Ask for help. Develop solutions to new and ongoing problems by asking for help, by being open to others' ideas, or by joining a support group.

Build in a sense of family togetherness. Take time out to decompress and simply enjoy being with one another. Include your loved one who has the disease in your relaxing activity, be it music, family charades, or a meal.

Maintain traditions. Continue your family's meaningful activities and celebrations. These provide continuity and are a reminder of your family's history and love. However, also recognize that certain holidays can be highly stressful and anxiety-producing. Give yourself permission to miss a celebration if you feel that's best for you or your loved one.

Conclusion

It is essential to acknowledge that everyone is human and that each person is dealing with multiple stressors all at the same time. Express your concerns and fears. Ask each other for support. Reach out to family members who are distant and try to express some of your own feelings and fears. This can open the door to a genuine exchange and a new understanding. Most importantly, stay close to your loved one who has the disease. Remember who they are, what you love about them, and that each moment you share is precious.

Talking to Children and Grandchildren

Elaine S. Book, MSW, RSW

Diane Breslow, MSW, LCSW

A diagnosis of PSP, MSA, or CBD for an individual is actually a diagnosis for the family. It changes life for everyone in the family, including children of all ages. Supporting the children in the family will require preparation; awareness of age, stage, and personality of the children; and your own acceptance of, or coming to terms with, the condition.

Possible Effects on Children

Just as the symptoms of PSP, MSA, and CBD vary and change over time for each person, so do the reactions, emotions, and needs of each individual child within the family. Their adjustment to hearing about the diagnosis and to the progression of the condition may be related to specific symptoms, the nature of the relationship with the affected individual, the family structure, the family's social supports, and other influences such as culture, religion, and outside influences.

BEING A CAREPARTNER (continued)

Common feelings some children may experience include:

- Shame or self-consciousness about the way the condition presents (for example, a parent in a wheelchair)
- Anxiety about the stress in the family as a result of the diagnosis and symptoms of the condition
- Sadness, fear, anger, and grief regarding the changes and loss of experiences with the person who has PSP, MSA, or CBD
- Loneliness when one parent spends increasingly more time providing care to the person with the condition
- Worries about their risk of developing the condition, about the families' finances (especially if income has changed and care costs have increased), and about the impact of the condition on their own future aspirations and decisions
- Feeling overwhelmed by caregiving responsibilities
- Frustrations with their own activities being restricted (such as not wanting to bring friends home, or feeling bad about going out while one parent is home potentially burdened by symptoms and the other parent may be burdened by caregiving responsibility)

Remember that young children cannot always identify their emotions and instead may express them through behaviors (for example, increased clinginess, fears, inattention at school, attention-seeking behaviors).

Living with a challenging illness in the family can also have positive effects on children. The experience can strengthen family relationships, help improve coping skills, and instill a sense of pride and confidence in one's ability to handle life's trials. In addition, children who are exposed to chronic illness develop an earlier, and strong, sense of empathy and compassion, which sometimes leads to life-changing educational and career choices. Just as a caregiver and affected spouse may experience personal growth as a result of the illness, children too may grow and develop in unanticipated ways.

Be mindful that as children grow up, there may be difficult times or behaviors that are not related to the disease in the family but are more likely a result of the child's or teen's social and emotional developmental stage. Children who are managing daily stressors in their own individual lives may have a harder time coping with the illness in the family.

What, when, and how to talk with your children or grandchildren about these diseases

Many parents are understandably concerned about what, when, and how to tell the children about the diagnosis.

Whatever the age of the children, think about:

- Sharing the diagnosis and the process of having received the diagnosis
- Providing information about PSP, MSA, or CBD that is appropriate to the child's age and developmental stage
- Using language that is easy to understand and that focuses on symptoms and behaviors that the child sees and can relate to
- Communicating your best understanding of disease progression, in response to the child's questions and in amounts of information that the child may be able to digest at one time
- Practicing what you are going to say before talking with the children
- Planning for a time to talk that will be free of interruptions, especially for the initial conversation about the diagnosis

Below are examples of easy-to-understand language that address some typical concerns that children may have:

- PSP/MSA/CBD is a progressive (changing) neurological (brain) illness that can affect a person's physical movements and other ways the body works. Sometimes these are changes you can see (poor balance that leads to falls, voice changes), and sometimes they are changes you can't see (forgetfulness, sad mood) but that still affect your parent/grandparent.
- PSP/MSA/CBD is not contagious. You cannot get it from touching someone or even being around them. It is rare for PSP/MSA/CBD to be genetic (inherited or passed down in your family).
- There are different treatments to help with the symptoms (physical and mental signs), including medications (pills). There are also physical therapists, occupational therapists, and speech therapists to help with some of the symptoms.

When to talk with children/grandchildren

In general, secrecy can be more harmful than sharing the truth about health issues, as children tend to be quite perceptive. In addition, children are usually more afraid of the unknown than they are of information that is presented at their level. Children are inclined to say that they want more information rather than less, and earlier on in the condition rather than later. They also want to know what to expect as the disease progresses. Be sensitive to the timing of your discussions. For example, bring up the topic when everyone is least burdened, not at the end of long day when you/they are tired, or before a test or major sporting event, or when rushing out the door.

How to talk with children/grandchildren

Your attitude and the way the diagnosis is presented can affect how children cope from the start. You want to be honest, hopeful, and mindful of tone of voice and choice of words. Encourage children to let you know what is on their minds and to ask questions. Communicate honestly, openly, and frequently about how this disease impacts the family. Discuss worries, find solutions together, and highlight what is working well. Consider asking, "How are things different for you now that Mom has MSA?" or "Is there something that I can do that would be helpful?" By acknowledging a child's feelings and fears and by providing the responses and reassurances children need, you will help replace their fear with knowledge. You want to provide an environment that is comfortable for children to ask questions. Answer the specific question the child has asked. And it is ok if you do not know all the answers or if you are unsure how to respond to difficult questions. Let the children know that their question is a good one and that you will get back to them with a good answer once you have thought about it.

Also, consider talking about research, possible new treatments, and specialists who are working hard to improve treatments and quality of life for people with PSP, MSA, and CBD.

Ways to support children and maintain family wellness

Children may want to talk about the condition, but not with you. Ensure that they have someone to talk to (a friend, parent of a friend, teacher, coach, relative, member of clergy, or healthcare professional). Connect with other adults in their life who may offer support to children as needed. These adults may also be able to keep an eye out for changes in children that may be related to disease progression or the family's coping. Peer support is another option. Your neurologist, healthcare team, or organization may be able to match your child with another child in a similar situation. If a child displays significant behavior changes that begin to interfere with their normal day, seek a referral to a social worker or other mental health professional.

BEING A CAREPARTNER (continued)

Journaling is a strategy that provides a safe space to express thoughts and feelings that children may not want to share with anyone else. This can include writing, drawing, poetry, random words, or images. Purchase a journal book and some pens, and suggest some prompts (for example: Something I found difficult today, Something I am worried about, Something that made me smile, etc.).

Children should be encouraged to continue leading their lives and remaining active and involved with their interests, hobbies, and friends. Check that your children have support systems at school, in the family, and in the community. Arrange for younger children to have play dates. Ask extended family to spend special time with your child. As children grow into teens and young adults, they may need these resources and support to encourage and validate making decisions that are right for them and their future.

Rather than isolating children from the person with the condition, find ways to allow the children to assist and to be involved. Be creative in helping the child to continue the connection with the person with PSP, MSA, or CBD. Children might want to hold packages for the person, push a wheelchair, sign greeting cards, be responsible for some household chores, play board games, tell jokes, watch a TV series, read a book, or help make a favorite recipe. Being involved in these ways will provide children with the opportunity for personal growth and for coming to terms with the illness in a healthy, productive way. Empower children by encouraging them to be involved in a fundraiser or awareness event. Being personally involved with chronic illness expands one's horizons and opens one's heart to being non-judgmental about others' limitations or differences.

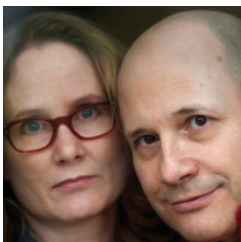
Conclusion

In general, children need to feel secure knowing that you will be able to manage whatever comes, that you will get the help that is needed, that you love them, and that you will all be ok—maybe different, but ok.

Children, like adults, need permission and time to grieve the changes and ongoing losses in their lives. Understandably, they may have to work through some sadness before adjusting to a new reality. Focus on what still exists—love, time together, and shared interests.

Resources

- Pittsburgh Healthcare Report: This site has some good general information on prime of life neurodegeneration. • www.pittsburghhealthcarereport.com/helping-kids-cope-when-a-parent-is-sick/
- Marjorie E. Korff PACT Program: This site details how to support children at different ages. See the left sidebar of this page for age-specific tips.
 - www.mghpact.org/for-parents/parenting-principles/developmental-perspective/overview
- *How to Help Children Through a Parent's Serious Illness* by Kathleen McCue
- *Raising an Emotionally Healthy Child When a Parent is Sick* by Paula Rauch and Anna Muriel
- *The Etiquette of Illness* by Susan Halpern, with a chapter "Talking to Children about Illness"



Facing Loss and the End of the Caregiver Role

Diane Breslow, MSW, LCSW

Throughout the course of one's life, every loss helps prepare us for subsequent losses. Because of the progressive nature of PSP, CBD, MSA, and other neurodegenerative diseases, caregivers and others close to the patient have already experienced and grieved the step-by-step loss of the person they knew and loved. Yet, the death of the person you were caring for brings with it an additional loss and subsequent life transition: the end of your caregiver role and a period of mourning for that role. It is the beginning of a new and uncharted path in your own life.

The purpose of this article is to help you with the grieving process and to map a new course for yourself. Grief is not necessarily predictable nor the same for everyone. Every person moves through the series of steps at their own pace. Therefore, the suggestions contained here are meant to be general guidelines.

Grief

The grieving process is unique to each individual, and its so-called stages are not sequential or linear. Nevertheless, each person is likely to pass through similar phases of grief and to experience common issues and emotions. In 1969, Elisabeth Kubler Ross was the first of many subsequent theorists to posit a framework for the stages of grief.

Her theory is comprised of five stages:

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

A more recent theory, The Grief Cycle, posits the emotions of grief in a dynamic circle, rather than in stages (see the book by Shelly O'Brian listed with the Resources at the end of this chapter), as follows:

- Shock: Numbness, disbelief, inability to think straight
- Protest: Acknowledging the deep sorrow; consequently feeling anger, guilt, sadness, fear of what's next, yearning. Feelings, such as anger, at the person who died or at those who tried to help them are normal. Guilt is also normal: for example, guilt about the death of your loved one, guilt that you have survived, or guilt that you feel a sense of relief that your caregiving duties are over.
- Feeling of disorganization: Depression, loneliness, anxiety, confusion (perhaps because you feel relief that the suffering has ended not only for the one you cared for but for yourself as well), loss of identity, vulnerability
- Reorganization and redefining of self: A gradual return to "normal" functioning with new habits and routines but still feeling "not quite right"

Give yourself permission to experience and feel these emotions, and their fluctuations. Expect "anniversary" grief reactions on the dates of memorable occasions and holidays. With that in mind, mentally allow yourself to grieve for at least one year of seasons, holidays, and anniversary events without your loved one. Even consider planning for anniversary reactions. For example, think about what would feel right for you on a particular occasion. Let your family and friends know this, and ask them to honor your wishes. Do as much, or as little, as you can handle and allow yourself to be flexible and change plans if you feel you need to. Anniversary times are stressful enough as is, and grief can intensify that feeling of stress.

BEING A CAREPARTNER (continued)

Moving on—making a new life after caregiving

Inside the circle of grief is the resolution, which the theory calls Recovery. Recovery means learning to live apart from and in spite of the loss. What can you do to help yourself arrive at this place of Recovery, or “Now what?”

Take Care of Business

- In view of the multiplicity of your losses—the loss of a dear loved one, the loss of your role and perhaps identity, the loss of much that filled your days and your mind—please, allow yourself time before plunging into the tasks of sorting through belongings, settling finances, passing on personal items, and managing family business matters.
- Delay making major life changes, such as selling a home, moving, or leaving a job.

Take Care of Yourself

- The basics: Nourishment, hydration, rest, exercise, relaxation breathing or meditation, and making and keeping doctor and dentist appointments.
- Exercise: Regular exercise contributes to improved circulation, flexibility, sleep, and sense of well-being.
- Breathing: Breathe in through your nose while counting to four, then exhale through your mouth to a count of four. Repeat 5 to 10 times.
- Accept offers of companionship and help from others.
- Rediscover what you enjoy.

Interact with People

- Perhaps you will want to or need to reconnect with people that you may not have seen frequently during your caregiving days and years.
- Reach out to trusted friends who will listen to you and support you in your grieving process and in building a new life.

Develop Daily and Weekly Routines

- Take time to figure out how you might want to spend your newfound time.
- Take small steps toward the goal of establishing new routines, activities, and interests.
- Structure at least a few days a week around a particular activity, class, job, or volunteer responsibility that gives you purpose and meaning. Perhaps schedule an activity where others rely on your presence.
- Volunteering: Many organizations offer volunteer opportunities on weekly schedules and also as one-time events. Consider how much time you might want to give. Decide whether you want to utilize your professional expertise or try a new area of interest. Think about location: Is it important to you to volunteer in a particular neighborhood, such as close to home or work? If you choose, you can even find volunteer jobs that you can do from your own home, such as recording audio books or making phone calls.

Continue Your Own Healing

- Talk about your loss. Face your thoughts and feelings about it.
- If you belonged to a caregiver support group, consider returning to the group at least once for reminiscence, goodbyes, and closure—or even for longer, if you are so inclined.
- Think about whether you would gain solace through volunteer work for CurePSP or another organization related to the disease or particular issues you were dealing with.
- Resume or start a creative endeavor, such as painting, music, crafts, or writing. Any of these activities enable self-expression and the possibility of seeing things from a new perspective.
- Join a bereavement or grief support group, either in person or online. If, in the past, you have been a member of support groups, you know firsthand some of the benefits: commonality among participants, feeling less alone, receiving understanding and feeling understood, the reward of reaching out to others, socialization and relationships, information, and resources.
- In addition to planned online groups, there is an app called Goodgrief. It asks you a few questions about your loss, offers additional filters, and then connects you on a one-to-one basis to people in similar situations.
- Turn to your faith or faith group for guidance.
- Keep alive the good memories of your loved one. Talk about them. Reminisce about the positive moments you and your loved one shared. Retain precious mementos. Enjoy special photographs with your friends and family members. Include children or grandchildren in conversations and, in general, in the processes of grieving and healing. Create a memory book. Throughout, bear in mind that, although death ends a life, it does not end a relationship or your feelings about the person.
- Reflect on, and embrace, the personal rewards of having been a caregiver: Did you learn patience? Acceptance? Taking one day at a time? Did you discover inner strengths and resources you didn't know you had? Do you have a sense of pride and contentment that you were there for your loved one?
- Be aware that grief may re-appear even after you thought it might be over.
- Reach out for professional help from a psychotherapist or bereavement counselor, particularly if grief persists for many months, interferes with your day-to-day life, causes you to lose (or not regain) interest and pleasure in life, or makes you preoccupied with thoughts of death or a desire to die.

The take-away message

We hope these ideas and suggestions provide you with directions, options, and affirmation as you grieve the loss of your loved one and map a new course for your life. Grief and moving on are processes that take time, are not necessarily linear, and are different for every individual. For many people, grief continues—in varying degrees and occasions—for a long time. Give yourself the time, the space, and the course that is right for you.

Resources

- AARP • 888-687-2277 • www.aarp.org
- Hospice Foundation of America • 800-854-3402 • info@hospicefoundation.org
• www.hospicefoundation.org
- National Hospice and Palliative Care Organization
• www.caringinfo.org/i4a/pages/index.cfm?pageid=3367
- National Library of Medicine • <https://medlineplus.gov/caregivers.html>
- *Peaks and Valleys – Integrative Approaches for Recovering from Loss*
by Shelly L. O'Brian, LCSW, 2014.
- *Today's Caregiver* Online Magazine, After Caregiving topics • www.caregiver.com/topics/caregiving

The 7 Deadly Emotions of Caregiving

Paula Spencer Scott

Nobody would ever choose a smiley face as the perfect symbolic emoticon for a caregiver. Caregiving for an ailing loved one is just too stressful, often triggering damaging emotions that can not only undermine your good work but harm your health, as well. Here's how to cope:

Caregiver emotion trap #1: Guilt

Guilt is virtually unavoidable as you try to “do it all.”

What causes guilt: Guilt stems from doing or saying what you believe is the wrong thing, not doing what you perceive to be enough, or otherwise not behaving in the “right” way, whether or not your perceptions are accurate. Caregivers often burden themselves with a long list of self-imposed “oughts,” “shoulds,” and “musts.” A few examples: I must avoid putting Mom in a nursing home. I ought to visit every day. I shouldn't lose my temper with someone who has dementia.

Risks of guilt: Caregiver guilt is an especially corrosive emotion because you're beating yourself up over faults that are imagined, unavoidable—or simply human. That's counterproductive at a time when you need to be your own best advocate.

What you can do: Lower your standards from ideal to real; aim for a B+ in the many aspects of your life rather than an across-the-board A+. When guilt nags, ask yourself what's triggering it: A rigid “ought”? An unrealistic belief about your abilities? Above all, recognize that guilt is virtually unavoidable. Because your intentions are good but your time, resources, and skills are limited, you're just plain going to feel guilty sometimes—so try to get comfortable with that gap between perfection and reality instead of beating yourself up over it.

Caregiver emotion trap #2: Resentment

This emotion is still so taboo that many caregivers are loathe to admit it.

What causes resentment: Caregivers often feel put-upon and upset because of imagined slights by others, including siblings and adult children who don't do enough to help. Caregiver resentment is especially felt toward the person being cared for, when the caregiver's life feels hijacked by responsibility and out of her or his own control.

Risks of resentment: Without enough support or noncaregiving outlets, feelings of being ignored, abandoned, or criticized can fester into anger and depression.

What you can do: Simply naming this tricky emotion to a trusted confidante can bring some release. Try venting to a journal or anonymous blog. Know that resentment is a very natural and common response to long-term caregiving, especially if your work life, marriage, health, or outside activities are compromised as a result. Know, too, that you can feel this complicated emotion yet still be a good person and a good caregiver.

See also: Chapters on Managing Symptoms and Managing Care and Getting Professional Support.

Caregiver emotion trap #3: Anger

Some people outwardly show their anger more than others, but almost no one is never angry.

What causes anger: We get mad for reasons both direct (a balky loved one, an unfair criticism, one too many mishaps in a day) and indirect (lack of sleep, frustration over lack of control, pent-up disappointment).

Risks of anger: Chronic anger and hostility have been linked to high blood pressure, heart attack and heart disease, digestive-tract disorders, and headaches. Anger that builds up unexpressed can lead to depression or anxiety, while anger that explodes outward can jeopardize relationships and even harm others. Managing caregiver anger not only helps your well-being but makes you less likely to take out your fury on your loved one.

What you can do: Rather than trying to avoid anger, learn to express it in healthy ways. Simple deep-breathing exercises can channel mounting anger into a calmer state, for example. Talk yourself down with soothing chants: It's okay. Let it go. Ask yourself if there's a constructive solution to situations that make you angry: Is a compromise possible? Would being more assertive (which is different from anger) help you feel a sense of control? Laughing at absurdities and idiotic behavior can provide a healthier biological release than snapping.

Caregiver emotion trap #4: Worry

A little goes a long way, but sometimes we can't turn off the fretting.

What causes worry: Good intentions, love, and wanting the best for your loved ones are the wellsprings of worry. Focusing intensely on the what-ifs provides a perverse kind of comfort to the brain: If we're worrying, we're engaged. Of course, that ultimately triggers more worry and upset because it's engagement without accomplishing anything.

Risks of worry: Being concerned is harmless. Over worry and obsessing, however, can disrupt sleep, cause headaches and stomach aches, and lead to mindless eating or undereating.

What you can do: If you notice worrying thoughts interfering with getting through the day or sleeping at night, force a break to the cycle. Try setting a timer and resolving to focus on something else when the five minutes is up. Then flip negative thoughts to their productive side: How can you help? Can you call someone? Are there possible solutions? And don't be shy about seeking out a trained counselor to help you express and redirect obsessive ruminations more constructively.

Caregiver emotion trap #5: Loneliness

Your world can shrink almost before you realize what's happened.

What causes loneliness: Friends may back away out of uncertainty or a belief they aren't wanted. Intense time demands lead you to drop out of outside activities. If you're dealing with dementia, the loss of your loved one's former level of companionship is another keenly felt social loss adding to isolation.

Risks of loneliness: Your very brain is altered: People with large, rich social networks have different brain structures, new research finds. Loneliness seems to curb willpower and the ability to persevere, and it can lead to overeating, smoking, and overuse of alcohol. Lonely people also have more cortisol, the stress hormone. And social isolation is a risk factor for dementia.

BEING A CAREPARTNER (continued)

What you can do: Expand your social circles, real and virtual. Arrange respite help, so you can add at least one outside activity, such as one you've dropped. Take the initiative to reach out to old friends and invite them over if you can't get out easily. Consider joining a support group related to caregiving or your loved one's illness. In online support groups, you can find kinship with those who know just what you're going through.

Caregiver emotion trap #6: Grief

Don't think this one applies yet? Think again.

What causes grief: Although most people link grief with death, anticipatory grief is a similar emotion especially felt by caregivers who are coping with a loved one's long-term chronic illness.

Risks of grief: "Long goodbyes" can trigger guilt as well as sadness if one mistakenly believes that it's inappropriate to grieve someone still alive. Mourning the loss of a beloved companion is also a risk factor for depression.

What you can do: Know that your feelings are normal and as painful as "real" (postmortem) grief. Allow yourself to feel sadness and express it to your loved one as well as to supportive others; pasting on a happy face belies the truth and can be frustrating to the person who knows he or she is ill or dying. Make time for yourself so that you're living a life outside of caregiving that will support you both now and later.

Caregiver emotion trap #7: Defensiveness

Protecting yourself is good—to a point.

What causes defensiveness: When you're doing so much, it's only natural to bristle at suggestions that there might be different or better approaches. Especially if you're feeling stressed, insecure, or unsure, hearing comments or criticisms by others, or reading information that's contrary to your views, can inspire a knee-jerk response of self-protection: "I'm right; that's wrong!"

Risks of defensiveness: While nobody knows your loved one and your situation as well as you do, being overly defensive can make you closed-minded. You risk losing out on real help. You may be so close to the situation that you can't see the forest for the trees. For example, a social worker or friend may have a perspective that points to what really might be a better way.

What you can do: Try not to take everything you hear personally. Instead of immediately getting cross or discarding others' input, vow to pause long enough to consider it. Remember the big picture. Is there merit in a new idea, or not? What you're hearing as a criticism of you might be a well-intentioned attempt to help your loved one. You may decide things are fine as is, and that's great. But if you start from a point of calm and confidence, the focus becomes (as it should be) your loved one, not you.

Paula Spencer Scott is the author of *Surviving Alzheimer's: Practical Tips and Soul-Saving Wisdom for Caregivers*.

Make Meaning to Stay Positive

Janet M. Edmunson, MEd

Taken from her book, *Finding Meaning with Charles*, and used with permission.

It wasn't until about the third year of Charles's disease that the Serenity Prayer had its greatest impact on me. But I have always loved it, and it means the most to me when I am going through tough times: "Grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference."

I have really latched onto the concept of "accepting the things I cannot change." Though we tried to fight it, Charles's disease was going to take away his abilities, and eventually, his life. Our choice was to accept that or deny it.

I don't know for sure what Charles's choice was. He was determined not to let the disease change his life and goals. He tried hard to keep contributing as best he could. That was how Charles tackled everything in life. He denied the obstacle and set out to conquer it. He wouldn't succumb. He fought all the way to the end. Is that acceptance or denial?

I, however, consciously chose to accept it and make the most of it.

My greatest learning through this experience came when Charles and I attended the Mind/Body Medical Institute program which, at the time, was held at Beth Israel Deaconess Hospital in Boston. The instructor, Peg, talked about acceptance, explaining that the way to accept the things that we have no control over, such as an illness, is to make meaning out of it. Wow! Make meaning out of it! Her explanation suddenly allowed me to consciously look at what Charles and I were going through and identify where it helped us grow and where it allowed us to have an impact on others that we wouldn't have had without the adversity of his disease.

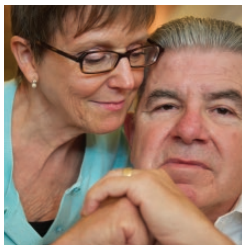
Taking a proactive approach to making meaning out of our situation helped me to positively focus on the opportunities and not plunge into depression. I was determined to help Charles reach whatever potential his life could give. And I was amazed to see how Charles became even more influential—even after he could no longer talk. As a caregiver, I found it important to focus on this greater purpose. My goal for caregiving went beyond making sure Charles was safe and physically cared for. I wanted to ensure that he still lived life to the fullest—to whatever degree the disease would allow.

BEING A CAREPARTNER (continued)

Accepting Charles's disease and making meaning out of it didn't mean that we didn't feel pain. Coping with this type of degeneration was difficult physically and emotionally for Charles, the person with the disease, as well as for me, the caregiver. We faced many trials—some successfully, others not. But we both became better people through experiencing his disease.

M. Scott Peck starts his book *The Road Less Traveled* with the sentence "Life is difficult." He goes on to explain that once we accept this, we can begin to make the most of life. Charles and I had discussed this concept a number of times when we faced problems at work or with other people. The misfortune of his disease forced us to face our greatest life difficulty, truly testing our ability to accept adversity and then move on.

I don't know of anyone who expressed this thought better than Viktor Frankl in his book *Man's Search for Meaning*. Frankl survived the atrocities and indignities of a concentration camp in World War II. He realized there that to renew our inner strength, we need to have a future goal. He quoted Nietzsche's words, "He who has a why to live for can bear with almost any how." I found that "finding meaning" is a way to define the why. The act of looking for and finding meaning in Charles's disease focused and empowered me.



PART THREE

Making Plans



Estate Planning

You can read or download CurePSP's Estate Planning Guide and Organizer at <http://plannedgiving.curepsp.org> or contact Joanna Teters at teters@curepsp.org or call 347-294-2871 to have one mailed to you.

There are several benefits to making an estate plan:

Peace of mind for you – An estate plan is designed to provide for you during life should the unforeseen (your incapacity) happen and for your family when the foreseen (your passing) does occur.

Peace of mind for your family – An estate plan and documents will help guide your family if they need to make difficult decisions about your care and provide the authority they might need to do so, and to know what to do when you are gone. Consider your plan a final gift to your family and other loved ones at the very time they need it the most.

Distribution that you want – Without an estate plan of some type, the laws of your state determine what happens to your property. This is called intestate succession (property inheritance when there is no will). Very likely the distributions it dictates will NOT be the ones you would have chosen. And no state distribution law provides for gifts to friends or charities, or makes provisions for your pets. Make sure what you've earned and accumulated in your lifetime goes to help those you love and causes you care about.

Provide for your family – An estate plan is especially important if you have minor children, as it will name a guardian to care for your children. In many instances, it will establish a trust to help ensure their financial well-being.

Financially wise – A good estate plan will help streamline the distribution process, minimize administrative costs, and possibly reduce taxes that might otherwise be owed. That means you leave the most you can to the people you love and the causes you care about.

Related to your final wishes

- **Will.** A valid will is generally typed, dated, and signed by you as well as two legally competent witnesses. States differ as to whether a handwritten will, with or without witnesses, is valid.
- **Revocable Living Trust.** This can be used instead of a will as the main document disposing of your property. You might hear it referred to as a “living trust” or “RLT.” The trust is created while you are living, most often people serve as their own trustee, and the power to change and even revoke it can be retained. The living trust becomes irrevocable upon your death. A living trust requires that you actually transfer your property into it for it to be effective.

There are pros and cons with each approach, and an estate planning attorney can advise you as to which is best for your situation.

Note: Even if you decide upon a revocable living trust, you should still have what is called a “pour-over” will. It catches any property that was, intentionally or inadvertently, left out of the trust during your life and is not transferred in another way. While this property will still need to go through probate, it will eventually be distributed according to your trust instructions instead of being distributed under state law provisions.

- **Beneficiary designations.** These are the forms you fill out when you do things like open a bank or stock brokerage account, establish an IRA or other type of retirement plan, or purchase a commercial annuity or life insurance policy. They specify who will receive whatever remains upon your passing (or the death benefit in the case of life insurance).
- **Form of ownership.** Jointly owned property that is “jointly owned with right of survivorship” passes directly to the surviving joint owner regardless of what the will or living trust might provide. This is most often seen with real estate but can involve other types of property as well. If you live in a community property state, your half of the community property will pass automatically to your spouse. These latter two means of passing property can have a profound impact on how your overall estate is distributed and should be considered as part of any coordinated plan.

Provide for physical and mental incapacity

- **Power of Attorney (POA) for financial matters.** This document grants to someone you trust the ability to act on your behalf for a variety of potential transactions and responsibilities. When the POA becomes effective, the extent of the authority granted can be tailored to your particular desires.
- **Power of Attorney for healthcare decisions.** This document appoints someone to make decisions for you regarding medical treatment if you are not able to do so. It allows you to specify who is in charge of making critical treatment decisions and, perhaps more important, who does not have that authority.
- **Health Care Directive.** Sometimes referred to as an “advance directive” or “living will” (not to be confused with a living trust), this specifies the type of end-of-life treatment you want to receive. It is a directive to the physicians treating you and for the person holding your Health Care Power of Attorney.
- **Physician’s Order for Life Sustaining Treatment (POLST).** This allows for your doctor, working with you, to document for the benefit of healthcare providers your wishes regarding resuscitation and other life-sustaining procedures.

Steps to having an estate plan

Depending on your situation, creating an estate plan doesn’t have to be overly difficult or expensive.

Here are some practical steps to get you started:

1. Take inventory of what you own. List all of your assets and their approximate value. Include pertinent information about that asset.
2. Make a list of tangible personal property such as jewelry, dishes, books, furniture—items other than real estate and investments—and who is to receive each item upon your passing. You may want to maintain this as a separate list rather than designating this in your will, for maximum flexibility.
3. Think about your goals for your estate plan, for example, whom you want to benefit, how you want to treat each of your children, any special needs that you want to provide for, what happens if you and your spouse both pass away close in time, and if there are charities or organizations you want to remember. Your attorney will most likely ask you about goals you didn’t consider, but at least you’ll have a head start on those that are most top-of-mind.
4. Consider whom you would like to name as your agents, e.g., the executor of your will, the trustee of your trust, and the person to hold your power(s) of attorney, and gather pertinent information about them.

MAKING PLANS (continued)

5. Go see an attorney, preferably one who specializes in estate planning. If you don't have one or know of one to call, check with family, friends, or co-workers for recommendations.
6. Follow through on whatever actions are decided upon in the meeting with your attorney. Rely on the advice of your attorney and other professional advisors as you make your decisions.
7. Share your plans with others. Key documents are of little or no value if no one knows what they say or where to find them when they are needed. This is especially true for the person(s) you have designated to serve as your personal administrator/executor under your will or the trustee of your living trust. It's also important to give loved ones at least a general sense of what to expect, so that there won't be surprises later on.

Frequently asked questions

Do I need to have an estate plan?

Yes. Regardless of the size of your estate, you still want what you have to go to those you love and care for and that your wishes are carried out. But a good estate plan does far more than that. It cares for you as well as your things. It grants a Power of Attorney for financial and health matters should you become incapacitated and states your wishes regarding final medical care. Your estate documents become a last expression of what you have valued in your life, expressed through a personal statement and by what you leave to whom. By being thoughtful and organized about your affairs, you will have left a final, loving gift to your family and friends.

Do I need to see an attorney?

Yes. Estate planning is a very complex area of the law and shouldn't be left to a one-size-fits-all arrangement. This is especially true when you have a combined family. What is best for your sister and brother-in-law is not necessarily best for you! While there is a cost involved in preparing your plan, it is modest compared to the value of having appropriate arrangements for your family, minimizing probate fees and costs, and possibly saving state and federal estate taxes.

How often should I update my plan?

It is a good idea to update your plan every seven to 10 years. Some people have an annual checkup with their attorney. Certainly whenever there is a significant event in your life such as the birth of a child or grandchild, sale of a business, retirement, or death of a spouse or other loved one, you should review your plan for necessary changes.

What if I have a plan but want to change one thing?

If your plan is fairly current, it is easy to make a change or two, such as adding a charitable beneficiary. Your attorney can prepare an amendment to your will (called a "codicil") or to your living trust. Many times this can be done quickly and for a nominal cost.

The information provided here is offered solely as general education information and is not intended to be a substitute for professional estate planning or legal advice. Because the laws of each state vary and your own circumstances are unique, you should seek the advice of your own attorney, tax advisor, and/or financial planner before deciding on a course of action and in creating your estate plan.

CurePSP Brain Tissue Donation Program

Lawrence I. Golbe, MD

*Supported by the
Eloise H. Troxel Memorial Brain Bank at the Mayo Clinic
Jacksonville, Florida*

CurePSP asks you to consider brain tissue donation when the clinical diagnosis is made. A brain bank at the Mayo Clinic in Jacksonville, Florida, one of the leading such facilities in the world, is supported in part by CurePSP, which provided the initial impetus for the brain bank's founding in 1998.

The final autopsy report from the brain bank provides the authoritative diagnosis as well as information about other brain changes that may exist, including those that may have contributed to a clinical misdiagnosis. The Brain Bank provides tissue samples to reputable scientists worldwide for investigation into the genetics and other aspects of the causes of neurodegeneration. Of course, the donor's name or other identifying information is removed before the tissue is shared outside of the Mayo Clinic.

After a few weeks, the next-of-kin will receive a comprehensive autopsy report that often offers closure after many years of suffering and caring for a loved one. The Brain Bank does not charge the family for its services. Neither does it require payment from researchers to whom it supplies brain tissue.

Questions and Answers

Q. Why make your decision in advance?

A. For several reasons:

- Your loved one can die suddenly, which is extremely stressful. A decision may have been made to donate the brain; however, without making prior arrangements, it is possible that the donation will not occur. The 24- to 48-hour window to perform the brain donation after death cannot always be met on short notice, especially on weekends and holidays.
- The patient, family members, and other loved ones should be involved in the decision. It may take time for everyone to come to an agreement. The Brain Bank coordinator is available to answer any questions and assist in making the arrangements.
- It can be difficult to locate a pathologist to perform the tissue collection. It is most important to have someone lined up in advance to make sure this procedure is accomplished within 24–48 hours after death.
- It is helpful to talk with family and friends, as well as the funeral home, about the planned arrangements. Planning in advance and the support of others will help during the time of grief. In addition to the brain donation, securing your loved one's medical records in advance is a significant help to the pathologist conducting the examination. Medical records show the disease progression. Records can be correlated with autopsy results.

MAKING PLANS (continued)

Q. Who may authorize a brain donation?

A. Legally, the patient and/or next-of-kin are the people who sign the Autopsy & Research Consent Form (available in our brochure).

If the patient's spouse is deceased, the oldest child is considered next-of-kin. In some states, the patient or next-of-kin may sign the consent form prior to death. In other states, consent is not legally binding unless signed after death.

Q. Will there be a need for any other tissue or organ donation?

A. No. In most instances where these diseases are suspected, only brain tissue will need to be examined for diagnosis.

Q. Where is the brain donation performed?

A. If death occurs in a hospital, and if the attending physician has ordered the procedure, the tissue collection will likely be performed in that hospital.

If death takes place in a nursing home, hospice, or at home, then the body will have to be transported to the funeral home, crematorium, hospital, or medical examiner's office for the collection to take place. In that case, the funeral home may charge for transport.

Q. Can there be an open casket?

A. Yes. Collecting brain tissue for diagnosis and research leaves no disfigurement to the body. You must inform the pathologist or diener (pathologist's assistant) that there will be an open casket.

Q. Will it be visibly noticeable that the brain has been removed?

A. Only on close inspection would anyone discover that a brain tissue collection has been performed.

Q. How do I find a pathologist who will perform the brain donation?

A. Please contact the Mayo Clinic Brain Bank coordinator, Rachel LaPaille-Harwood, at lapaille-harwood.rachel@mayo.edu or 904-953-2439. The Brain Bank has a list of pathologists in the U.S. and Canada to help you locate a professional in your area. You can also ask a funeral director or the patient's neurologist.

Q. Are there other ways to definitely confirm a diagnosis of neurodegenerative disease?

A. While clinical diagnosis has been greatly advanced, there is no way to confirm a diagnosis for most of these diseases other than by examining brain tissue.

Q. How long does it take for the autopsy report to be released?

A. Please allow up to 90 days for receiving the results of the autopsy. The report will be sent to the person who is listed as next-of-kin.

Q. I don't have any known brain disease; can I still donate my brain?

A. Yes, the Mayo Clinic Brain Bank actively searches for healthy brains. These serve as valuable control brains in research studies. It is very important to compare pathological changes in diseased brains with healthy brains. This helps scientists to better understand disease processes and to develop novel therapeutic strategies. Please contact the Mayo Clinic Brain Bank for more information on healthy brain donation. Please note that CurePSP cannot provide financial assistance for the donation of healthy brains. If you have any questions, you may contact Dr. Lawrence Golbe at CurePSP, at golbe@curepsp.org or 347-294-2872.

After your decision to donate has been made, important paperwork is required to perform a legal tissue collection. Please follow the guidelines below and complete all four forms. You can download the forms from www.psp.org/ineedsupport/braindonation. Or you may contact Joanna Teters at teters@curepsp.org or 347-294-2871, and we will send you a printed copy of the forms.

Please follow these seven steps:

1. Contact the Brain Bank coordinator, Rachel LaPaille-Harwood, who will help you understand the next steps and procedures. Phone: 904-953-2439, Monday-Friday, 7:00 a.m. to 3:30 p.m. (U.S. Eastern Time). Email: lapaille-harwood.rachel@mayo.edu
2. Enroll in the Brain Bank by completing the Brain Bank Questionnaire (in the above-mentioned brochure) and mailing, faxing, or emailing it to the Brain Bank ahead of time. It is important that this information be on record once the brain arrives at the Mayo Clinic.
3. Please send copies of the Medical Release Form to all of the following physicians and neurologists:
 - a. Those who are listed on the Autopsy & Research Consent Form
 - b. Those who have treated the patient for a neurodegenerative disease
 - c. Those whose clinical records could assist the researchers at the Brain Bank
4. The Medical Release Form authorizes physicians who diagnosed and/or treated the patient's neurological disease to send copies of their clinical notes to the Mayo Clinic. Only the patient or the next-of-kin can authorize the release of these records, which are important to the Mayo Clinic's researchers.
5. Complete the Autopsy Information Form. Make sure to have it placed in the patient's chart or medical files. The pathologist will sign and send the form, along with the brain tissue, to the Mayo Clinic Brain Bank.
6. Complete the Autopsy & Research Consent Form, signed by the patient and/or next-of-kin. Make sure to have it placed in the patient's chart or medical files. This is the actual consent for donation of a postmortem brain. This form can be signed only by the following individuals, and in this order of preference: patient, spouse, oldest adult child, parent, adult sibling, guardian, or power-of-attorney. For tissue collection to occur, the Autopsy & Research Consent Form, with original signature(s), and the Autopsy Information Form must accompany the deceased. Without a fully signed Autopsy & Research Consent Form, no brain donation is possible.
7. At the time of death, all family members and healthcare professionals need to know of the patient's wish to donate their brain. Please make sure that you have the pathologist's contact details available, so that they can be contacted immediately.

MAKING PLANS (continued)

The Brain Bank coordinator can answer any questions about the donation process, assist in getting copies of the patient's medical records for use in ongoing research projects, and help locate a pathologist in your area to collect the tissue.

If the patient dies at home, in a nursing home, or with hospice, the funeral home or crematorium will be involved in arrangements for the tissue donation. At times, the procedure can be performed at the funeral home or crematorium. In other cases, it may be necessary to transport the body to a hospital or medical examiner's office for the procedure. If the patient dies in the hospital, be sure that the physician has placed an order in the patient's chart to have the tissue collected and sent to the Mayo Clinic Brain Bank. We emphasize that the most difficult step in this process is to identify someone nearby who is willing and able to remove, prepare, and ship the brain quickly after death. This is the most important reason to make arrangements in advance.

Cost of Brain Tissue Donation

Neither CurePSP nor the Mayo Clinic imposes a charge for any part of the brain donation process. However, charges are typically imposed by the technician removing, preparing, and shipping the brain, and the funeral home that transports the deceased and provides a facility for brain removal. This cost typically ranges from \$500 to \$2,000 and is the responsibility of the family.

At CurePSP, we recognize that the expenses of the brain donation can be prohibitive for some families. A generous donor has contributed funds to create the CurePSP Brain Tissue Donation Fund. This has allowed CurePSP to provide financial assistance of up to \$750 to families who wish to donate brain tissue but may have financial constraints. If your family needs assistance with the tissue collection costs, please contact Joanna Teters at 347-294-2871 or teters@curepsp.org. We emphasize that this program has limited resources and is intended only for families whose financial situation would not otherwise allow brain donation to occur.



PART FOUR

From Our Families:

Carepartners' Perspectives and Pointers



I. Patience

Bill Furlow

A retired journalist and communications consultant, living in Greensboro, North Carolina

As a person who spent seven years as a PSP caregiver, I have thought about the most important gift I would give others in similar situations if I could.

The answer is: Patience.

When you're a caregiver for someone who is afflicted with PSP, all expectations about how long things take to do or how difficult they can be to accomplish go right out the window. You and your loved one simply cannot do in a day or an hour what you once could do with ease.

Here are a couple of dictionary definitions of patience that may feel familiar:

- The bearing of provocation, annoyance, misfortune, or pain without complaint, loss of temper, or irritation
- The ability or willingness to suppress restlessness or annoyance when confronted with delay

Bear annoyance without complaint? Suppress restlessness over delay? That's not easy for most of us to do.

Just as we know that courage is not the absence of fear but rather the ability to perform while afraid, patience is not the absence of frustration over delays or the difficulty in performing formerly routine tasks. Patience is the ability to power through frustration while maintaining an even keel and, we hope, holding onto our sense of humor.

To remind myself to try to be patient while my wife was in the late stages of her disease, I tried to think about how my showing, or failing to show, patience must appear from her perspective. It would not be unrealistic for me to be called upon to be patient 40 times in a given day. If I had a 90% success rate, then four times during that day I failed to show patience. I lost my cool or snapped or said something I later regretted. And what was she likely to remember at the end of that day: the 36 times I was patient or the four when I wasn't? Even now, it hurts to think about that.

As caregivers, we must learn to slow our internal clocks. For me it was important to avoid putting my wife and myself in situations where we had to rush. Rushing leads to frustration, irritation, and, possibly, to accidents.

I learned not to extrapolate time because events rarely unfolded as I wanted them to. If I really wanted to jinx myself, I might think, "We have 20 minutes to get in the car, and all we have to do is use the bathroom and brush hair. No problem." Famous last words.

Instead of making assumptions about the future, I learned to try to envision it. I'm talking about the next hour, or 15 minutes, or five, or even one. What needs to occur in that time, and what do I need to do to make it happen? I would literally picture the steps in my mind.

Another way I tried to conjure up patience was to attempt to see the big picture: Is it really a tragedy if we're five minutes late for church?

One other was to tell myself in stressful moments, "This is unpleasant, but it's not intolerable. I can do this."

It is hard for caregivers not to become frustrated by their frustrations. But we're better off when we accept that we're going to be frustrated—often—and just see it as part of life right now.

I said I would give all caregivers the gift of patience if I could. Alas, I cannot. Instead, I'll just say that nothing I've written here is to suggest you beat yourself up every time you lose your patience. We're all human and can only do our best. Please save some of your patience for yourself.

II. A Carepartner's Comments to the October 23, 2009, Chicago CurePSP Conference

Chris de Brauw

A retired marketing research professional, living in Evanston, Illinois

I am the husband and primary caregiver of Ann de Brauw. In December 2007, almost two years ago, Dr. Simuni diagnosed Ann with PSP. To the best of Ann's and my knowledge, the onset of symptoms was in the middle of 2004. Altogether, we have been with the disease for about five years. Recent developments indicate, and were confirmed yesterday by Dr. Simuni, that Ann is in Stage 3.

Ann, like myself, is 62 years old. We are the parents of three grown boys, all of whom are happily married. We have two small grandchildren. We married young, and we expect to celebrate our 40th anniversary this December.

Ann is, and always will be, a foodie. She loves to eat, cook, and grow food. She buys fresh food daily, and she cooks from scratch or watches us cook. (I am learning). She has over 500 cookbooks and is a walking encyclopedia on cooking and recipes. Besides raising three terrific boys, plus all their friends who hung around our house, Ann took care of me, who lived within a hectic traveling career. She was a leader in local school issues, which included a term on the school board. She was an active member of the League of Women Voters, led and won a tax referendum, and went lobbying in our state capitol or at national education conferences. She also was a frequent volunteer for the Mental Health Association. Along with being an activist, she was known to be talkative, funny, very informed, and very smart. And, fiercely independent.

Today, Ann is a quiet fighter who has not lost her sense of humor. But she is no longer the person that people used to know so well. Her conversations are shorter, or even nonexistent. Much is conveyed by grunts and nods but also with pats, hugs, and kisses. Our relationship, today, is what we call "high touch." She relishes family times with her children and grandchildren.

Let's face it: The fact that we are here today, at this conference, includes a component of luck. Why? Because we know the diagnosis.

FROM OUR FAMILIES (continued)

I think all of us here at this conference have probably gone through three periods that Ann and I have experienced:

1. First, there is this vague sense that something is not right, but we have no idea what.
2. Next, something, or a series of things, happens that causes you to seek medical help. For us, this came after Ann fell backwards down the stairs for a second time. But, for a certain period (in our case, almost two years!), there was no good medical explanation for what was going on.
3. Finally, we have the right diagnosis, and we can get our priorities in order about how to manage the situation.

For Ann and me, getting confirmation that it was PSP has been crucial. It finally put us on a path to managing our lives and to maintaining some level of sanity. I feel for the thousands of people who must be out there—those who struggle with a person who falls, continually, for unexplained reasons, suffering injuries, stress, worries, and feeling lost.

Before I go any further, I want to salute everyone connected with the disease:

1. **Patients who are here today:** I admire your courage to face up to what the disease is like and what it has in store for you. I respect your struggle. I cannot imagine what it is like to have a disease that progressively gets worse and for which there is no cure.
2. **Caregivers:** We are going through an extraordinary experience, witnessing and managing a life that, step-by-step, needs different levels of support and, to be honest, a life that is being destroyed by the disease. If you are like me, you are very tired. It is a very draining experience indeed.
3. **Professionals:** I salute your efforts and your guts to deal with the quantity and quality of suffering that you see every day. Of course, we hope that you will find the causes and a cure, or at least a way to soften the impact of the disease.

But the reality today is that patients and caregivers are dealing with a degenerative, incurable condition that we have to manage in some way. Faced with this knowledge, I have simultaneously come to two conclusions:

1. I have to accept that this is the case: The disease is incurable and, ultimately, terminal.
2. I can and must do everything in my power to make this process as positive as possible.

One wonders, “Where does this positive stuff come from?” I’m not really sure. It just goes with my personality, I guess. I gain a lot of inspiration from other people with positive outlooks. If you ever want to find inspiration, I suggest you Google “Dalai Lama quotes.” It is amazing how many of his sayings apply to caregivers. My favorite quote, and I am paraphrasing here, goes something like this: “Human suffering is everywhere, but being happy or unhappy is still a personal choice.”

Over time, I have learned to express this drive for the positive in a number of ways.

1. Do whatever I can to keep Ann as well as possible, for as long as possible.
2. Keep our lives as normal as possible.
3. Give Ann control over things she can control.
4. Blame the disease when things happen.
5. Learn to accept help.
6. Look for easier, safer solutions to problems and mishaps.
7. Keep people in the loop.
8. Slow down.
9. Make sure to take care of myself—and our caretaker helpers as well.

Let's look at each of these goals in more detail:

1. Do whatever I can to keep Ann as well as possible, for as long as possible.

- Moved from a large home to a condo
- Found Ann a personal trainer
- Arranged, and receive major contributions from, a wide group of healthcare practitioners: movement disorders neurologist, Licensed Clinical Social Worker, rehabilitation physician and his patient-centered team, swallow test and training, computer training, home physical therapist, an aide from a home health company (who became our acquired family member)
- Maintain an excellent diet.
- Minimize medications.
- Keep Ann interested in life and invite friends to our home.
- Protect Ann from over-activity.

2. Keep our lives as normal as possible.

- Ann still shops almost every day, and she directs the cooking.
- She still sleeps in a regular bed.
- She wears normal underwear whenever possible.
- She does her email.
- We have Sunday dinner with the “kids.”
- We celebrate holidays as usual.
- We still go to our country place almost every weekend.
- We eat in restaurants (familiar ones work the best).
- Until very recently, we continued to travel to favorite destinations.

3. Give Ann control over things she can control. For example:

- What we buy to eat
- Which movie we are going to see
- Where we eat out
- What we watch on TV
- What time she wants to go to bed
- What clothes she wants to wear

4. Blame the disease when things happen.

- Never get mad at the patient.
- Keep perspective and use self-talk: “No big deal.”
- See humor and use self-talk: “Never a dull moment.”
- Try not to panic when there is blood.
- Try not to blame yourself for accidents that, unavoidably, happen.
- Blame the disease.

5. Learn to accept help.

- People often want to help. Recognize and embrace that.
- Become better at letting the kids know that I need their help, and when.
- Return to the same places (shops, restaurants) with Ann, where we are recognized and where people reach out and show understanding.

FROM OUR FAMILIES (continued)

6. Look for easier, safer solutions. For example:

- Rearranging the furniture
- Purchasing a bike helmet for Ann to wear for protection

7. Keep people in the loop.

- Use email a lot.
- Recognize and thank people for their contributions as helpers.

8. Slow down.

- Learn to be patient.
- Tell myself: “You have all day.”

9. Make sure that I take care of myself and our caretaker helpers.

- Take time off and give time off to our paid helper.
- See a psychiatrist whom we have known for over 25 years.
- Hire a night nurse (three nights a week), allowing me to sleep through the night.
- Do yoga.
- Swim; play tennis.
- Play a lot of music.
- What I have not done: Attend a support group. (That does not mean that I have not reached out for all kinds of support.)

Hope to keep growing, learning, and finding meaning.

III. Products That I Remember Fondly, and Newer Ones from 2018

Steve Garcias

Products for Nutrition and Swallowing

- Nosey Cups
- Scoop Plates
- Comfort Curved and Angled Utensils
- Thick & Easy 4-Ounce Portion Control Cups
- Magic Cup Fortified Nutrition Vanilla Snack
- Thick Extra-Strength Powder
- Oral Care Swabs

Products for Mobility

- Elgin 3-Handle Ergonomic Walking Belt
- Karman Ergonomic Wheelchairs that help with standing
- Extra Large, Talking, Button Clock
- For Caregivers: Infant Optics DXR-8 Video Baby Monitor with Interchangeable Optical Lens

IV. Caregiver Checklist

Dan Heins

Caregiver to his wife who died from PSP at age 54; Atypical Parkinson support group leader in Louisville, Kentucky; board chairman of Parkinson Support Center of Kentucky

I think what would have helped me years ago would have been a caregiver checklist that lists many of the things you need to know or acquire to best take care of a loved one with PSP. I often share many of these ideas in my support group meetings. Some examples, and not in any particular order, are:

- U-Step Weighted Walker
- Soft Helmet (saved us several ER visits)
- Portable Suction Machine (saved us tons of ER visits)
- Panic Button, such as Life Alert
- Attention-getters: whistle, bellhop bell, cowbell, and wireless doorbell (wireless doorbell is my latest discovery... really great)
- Depends (they're more comfortable than you think)
- Hospital bed
- Hospital bedside tray or table
- Handrails in the bathroom and shower/tub
- Portable toilet with arm rails—one that can sit over a regular toilet (this prevents a broken toilet and toilet seat)
- Thick-It Powder
- Thick-It or Resource “ready to drink” containers of water, juice, tea
- Living Will
- Medical Power of Attorney
- Discuss the PEG decision early.
- Discuss the hospice decision early.
- Discuss funeral plans early.
- Record lots of video while your loved one can still speak.
- When to see a urologist about catheters or Foley catheters
- Home Urinalysis Test Kit (It's cheaper and easier to do it yourself. Only take any positive results to doctor.)
- Special hearing aids that work with a companion microphone (mine cost over \$4,500) or Mr. Microphone (a cheaper option)
- Remove clutter and eliminate all throw rugs/area rugs (easier said than done).
- Get a transport wheelchair.
- When do I need to have a Visiting Nurse come to the home? What duties should be expected of them?
- Oximeter (inexpensive and so important)
- Stethoscope (still learning to listen to sounds)
- Blood Pressure Monitor
- What can you expect insurance to cover, and what does it not typically cover?
Don't be afraid to appeal decisions and to insist that insurers use common sense.

FROM OUR FAMILIES (continued)

- What can you expect hospice to cover? What do they not typically cover or provide? Hospice regulations may have restrictions, but at the end of the disease, hospice is very comforting.
- Medicare eligibility, Disability eligibility
- Typical drugs that many PSP patients take. I realize this is a tough one, as no single list works for any one patient. But it can be a good conversation starter with your physician.
- Which drugs are always wastes of time—if there truly is such a list?
- Support group meetings in my area

V. Products and Practical Pointers Based on Experiences with Eileen

Al Nixon

*Retired engineer and president of a manufacturing company,
living in Farmington, Connecticut*

- Use a gait belt to assist your loved one out of a chair or off the floor.
- A wheelchair should have a seat belt.
- Always have a water bottle and throat lozenges with you for coughing spells.
- Purchase a baby's suction machine to clear mucus in the nose.
- Buy elastic-waist pants to make toileting easier.
- Buy coats in a larger size for ease of putting on and taking off.
- When installing grab bars onto toilet, you will need a toilet seat with metal bolts, not plastic.
- Mealtime: To keep plates from sliding, place them on a rubberized shelf liner.
- When lifting your loved one from the kitchen chair, place a piece of shelf liner under their feet to prevent them from sliding out from under.
- Before serving any hot liquid, test it yourself to make sure it is not too hot.
- Use mouth swabs or your finger to clear pocketing or “roofing” of foods.



VI. Tips for Taking Care of Your Loved One's Emotional Needs

Al Nixon

Brain disease is a very emotional and frightening malady. One does not know how the disease will progress, what symptoms will (or will not) occur, and whether they will cause pain and discomfort. Everyone with PSP has a different experience and progresses at a different rate. Your loved one's physician will ensure that they have the best care and medications for depression, anxiety, and other mental symptoms. But this is not all that can or should be done to help with your loved one's emotional well-being. I hope the following ideas will help caregivers contribute to their loved ones' emotional well-being. The list is in no particular order. Also, because each person is different, some pointers may not be appropriate or relevant to your situation.

Keep family and friends in your lives. Isolation is not good. With your loved one's approval, tell people what disease they have and what symptoms may eventually develop. Encourage family and friends to visit and remain involved with you. Educate others on disease features, such as slow reaction time. Demonstrate certain helpful responses—for example, allowing your loved one to take time to form a response to a question. Slow the pace of conversations. Address remarks directly to the person with the disease. Gather in small rather than large groups. I often recount the following incident, of which I am not proud, but was able to correct because my wife and I consulted with a social worker regularly. At the end of one of my wife's sessions, and during the routine, 10-minute summary for me, our social worker said, "During conversations when friends visit or when the home healthcare aide is there, Eileen feels like a 5th wheel. All of you are talking, and by the time Eileen can formulate her thoughts—usually 2 to 5 seconds—the topic has changed, and she cannot participate." The social worker continued, "It is up to you, the caregiver, to slow down the conversation, direct questions to Eileen, and keep her involved." Needless to say, I felt terrible. Fortunately, this was pointed out to me, and I was easily able to correct the problem. It had never occurred to me this was happening. I am sure this is also the case with many caregivers.

Encourage family to support the person and to demonstrate their caring. Ask appropriate family members to join you on visits to the doctor. They will also provide you with a "second set of eyes and ears" to ensure all the doctor's questions and your questions are answered.

Stay active and go outside. Take walks, including when your loved one is in a wheelchair. Visit a park or museum. See a movie. Eat a meal in a restaurant. (Make sure that someone accompanies your loved one to the restroom. Use family restrooms when available). For as long as possible, maintain appointments for your partner with the barber or hairdresser and manicurist. Sit outdoors when possible. Try to walk around a mall. When at home or when you leave the house, make sure that your loved one is "dressed up," so that they feel good about their appearance.

Stay involved in life. In all likelihood, your loved one has some special skills. Even if they can no longer perform them, ask for their opinions and let them help make decisions. With their input, generate a list of activities that make them happy and do those. For example, you may choose to play games, such as Scrabble, dominoes, or cards. However, be aware that the person with PSP will have difficulty holding objects. Also, because the person's eyes become fixed, their field of vision becomes smaller. Hand dexterity and visual changes will impact the person's ability to play games, especially those that spread across a table. Read a book together, or play music or books on tape. Because rapid-fire movies and TV shows may be difficult for your loved one to follow, try family movies such as Disney, sitcoms with straightforward plots, or nature programs.

FROM OUR FAMILIES (continued)

Continue to participate in your religious or spiritual practices. If you are accustomed to attending services, plan to maintain this. If that is not possible, ask your minister, priest, Rabbi, etc. to visit you in your home.

Stay informed about the disease and resources. CurePSP is an excellent advocacy organization. Its website provides up-to-date disease education, support groups, peer supporters, clinical trials, and more. Peer supporters are individuals who have had a family member with PSP, and some professionals. You can call these volunteers to ask their experiences and to gather new ideas and suggestions.

Ask for professional help. You and your loved one are dealing with a brain disease that can be very stressful. Don't shy away from seeking the expertise of a professional social worker or counselor. A psychotherapist can meet with you and your loved one together as well as individually. Sessions can be on a regular or as-needed basis. The most important advice is to find, and stay with, someone you trust and with whom you feel emotionally safe.

Make mealtime pleasurable. Put flowers on the table. Because food is one of the pleasures your loved one can still enjoy, let them eat what they want, within reason. To avoid choking hazards, cut food, such as grapes or hotdogs, into small pieces. Often, patients will select foods that are easiest for them to swallow—for example, cheesecake or ice cream. In time, by “going down the wrong pipe,” thin liquids will cause throat spasms. A speech therapist can help you and your loved one to manage this problem.

Demonstrate to your loved one that they are not a burden to you or others. Most people with PSP fear they will become a burden to their family. Show them that this is not the case. Keep active with your loved one. Maintain a regular and normal weekly schedule for both of you. Take care of yourself. Also, don't forget to hold your loved one's hand, give them a hug and a kiss, and tell them you love them as often as you can.

VII. Taking Care of Yourself

Al Nixon

Taking care of yourself is just as important as taking care of your loved one. You will not help your loved one if you are constantly stressed, tired, sick, frustrated, or angry. These emotions arise frequently, but by taking care of your physical and mental health, you will be able to cope with them better. Just as listed in the section about taking care of your loved one, many of these same thoughts and ideas apply to you.

Isolation is not healthy. You must get out and stay in touch with family and friends. Often, you will have to initiate these contacts, as many people are not sure how you want to handle your situation. Have coffee with friends. Go to the gym or health club to get some exercise. Play some golf, tennis, etc. Invite people to your home to visit. Don't feel guilty doing things for yourself. You need to stay connected to family and friends; you need them now, and you will need them when your loved one is gone.

Be careful with your alcohol consumption for several reasons:

1. It is not healthy for you and can impair your judgment and decision-making ability.
2. You never know when you might have to drive your loved one to the emergency room or an urgent care clinic.
3. The time will come when your loved one can no longer drive. You cannot afford to lose your license because of a DUI or endanger others because of impaired driving.

No doubt you and your loved one shared many household responsibilities. As soon as possible, you must learn how to assume the tasks that your loved one was fulfilling, such as paying bills; cooking; doing laundry; knowing which plumber, electrician, furnace company, etc. to use; and knowing where key documents and bank accounts are located.

There is no shame in seeking professional help for yourself. As you see fit, go to your minister, see a professional counselor, and keep regular medical appointments with your physicians and dentist.

It is easy to get so close to your situation that you do not see the warning signs that you need help. Hiring a cleaning person, a home health care aide, a companion, or adult daycare allows you to have some time to yourself for relaxation, rest, or errands. Keep an open mind to suggestions and recommendations from others, as they may see you becoming overwhelmed and stressed long before you do.

VIII. Desirable Attributes of Home Health Agencies, Aides, and Nursing Homes

Al Nixon

1. A good agency is responsive. For example, if a regular aide cannot work on a certain day, the agency finds a replacement. In addition, although most aides are technically competent, all of them will not necessarily have “chemistry” with your loved one. The agency should replace that aide right away. You should not waste time trying to work with and change the aide’s disposition, likeability, or “match” with your loved one’s personality.
2. Good aides take a real interest in your loved one’s well-being. They make the ill person feel normal. In a respectful and dignified manner, they help with daily baths, brushing teeth, dressing, applying makeup (if applicable), and so forth. They will also be engaged with your loved one. They should carry on conversations, play cards and board games, or go for walks. Many aides will be deferential to you, despite their experience level. Create an environment where they are encouraged to make suggestions and ask questions. Night shift aides are special people; finding a good one is not easy. Night aides are required to stay up all night and watch a TV monitor or sit bedside. The first few days, when you have a new night aide, you should wake up several times in the night to check that the aide is doing their job. If the aide is asleep or otherwise not alert to your loved ones needs, don’t hesitate to call the agency and request a new person.
3. Because PSP is a rare disease, very few healthcare persons are familiar with it. It is largely up to you to educate the agency, nursing home, or aides about your loved one, the disease, and the key tasks and skills required for good care.

IX. A Life Well Lived

Judi Nudelman

“A loving carepartner who was so lucky to have had so much to lose when PSP impacted Harvey”

My husband, Harvey, passed away peacefully at home January 17, 2018, after dealing with the effects of progressive supranuclear palsy for over five years. His life was a life well lived, both personally and professionally. Harvey’s five-plus years with PSP was also a life lived as well as possible.

We first heard the terms “possible PSP, progressive supranuclear palsy” in January 2013 on our first visit to the neurologist. For more than a year, I told our doctor, “something is wrong with Harvey.” Harvey, an agile racquetball and squash player, started having occasional falls. Harvey, always able to gather facts and quickly make decisions, struggled with the simplest decisions. Harvey, who loved life and always had a twinkle in his eye, was apathetic. Harvey, who loved people and lively social interaction, was quiet and detached. Harvey, the smartest person I knew, couldn’t analyze information. Our primary care doctor never investigated. He finally ordered an MRI and said, “Aging.” Then I decided to take Harvey to the neurologist, and he told us, “Mild cognitive impairment and possibly PSP.”

Harvey was unaware of how he was impacted. When asked how he was, he would say, “I am okay, but you’d better ask my wife. She doesn’t think so.” This held true for the rest of his life. He had a neurological component called anosognosia, meaning total lack of awareness. This was a good thing for Harvey: he wasn’t unhappy because he wasn’t aware of his losses. But for me, it meant, for the first time in our marriage, I was alone on a difficult journey, with total responsibility for making every decision.

Harvey, with a PhD in neuroscience, an accomplished researcher and teacher in the field, couldn’t access his neuroscience knowledge base. I had to learn about neuroscience and get the knowledge needed to be Harvey’s navigator, advocate, and decision maker for plans and actions related to his condition. Sadly, there was no PSP support group in Austin and very little local understanding of this disease. I participated in several of Janet Edmunson’s online CurePSP support groups, which helped prepare me for what might come. I also attended other types of local support groups and extracted information nuggets that applied. However, Harvey and I were experiencing a different world from the people in these groups, so their help proved limited. In spite of this, we managed to make our PSP journey a journey well-traveled.

My most important messages from our five-year journey are:

- Understand what might occur but know that the details of your future can’t be predicted. Though similarities exist with others, the journey is unique for everyone on it!
 - In the five years of his journey, Harvey never spent a night in a hospital or away from home. He was always in the home he loved, with friends and family often with him.
 - Harvey never had swallowing difficulties or problems eating.
 - Several weeks before he died, Harvey managed to go out with family on four separate occasions to celebrate holidays. What a gift that was for all of us!
- Caregivers need to pay attention to their own needs while caring for their loved one. Accept and reach out for help from friends and families. Cherish their company on the journey. Two years into

the journey, a dear friend insisted on helping, and she opened me up to help from many other friends. I very much needed this ability to get out and focus on myself regularly. As PSP caretakers, we run a marathon not a sprint. To function effectively as caregivers over a long haul, it's important to stay healthy and happy.

- Embrace new friendships and relationships. If you are lucky enough to have a local support group, check it out. I found Sarah and Bob, a couple in Austin that were on their own PSP journey. Sarah and I became each other's support group, and we remain very close friends to this day.
- Live every day as well as you can. Be a problem solver. Smile and laugh as much as you can! It's important to be positive and to enjoy each day. The days ahead of you are not likely to be as good as your today. Having breast cancer thirty years prior, I had learned and embraced a philosophy to enjoy every day with whatever it brings—and to keep my sense of humor and to laugh as much as I could. These attitudes gave me freedom to observe Harvey objectively and, as he declined, to problem-solve and determine new daily approaches and actions that could help.
- Plan for what comes after as the PSP journey progresses.
 - Consider donating your loved one's brain to research through the CurePSP Brain Bank at the Mayo Clinic. It's an important way to contribute to progress in fighting these diseases. This decision can't be last-minute, as there are steps and plans that must be done in advance. People at the Brain Bank can assist you with the details of your plans.
 - Think about things you will do when your loved one's journey is done. What friends and family do you want to catch up with? What travels would you like to take? Are there volunteer areas you care about? Be involved and lead a full life!

X: Thoughts about Hospice

Al Nixon, Steve Garcias, Roxi Padrid, and Fran Gardner

From Al Nixon

My wife, Eileen, was under hospice care for four weeks at home before she succumbed to aspiration pneumonia. As an overwhelmed caregiver 24/7, the thought of hospice never entered my mind despite her struggle with PSP symptoms and pain that can accompany them. Fortunately, my two youngest daughters (both in healthcare) said to me, "Dad, it's time for Mom to be in hospice care." This we did, and looking back, I can offer four important takeaways from my experience.

First: I waited too long to call hospice. Eileen suffered from severe abdominal pain due to constipation for several months prior to engaging hospice. During this period, she also had a urinary tract infection (UTI) and a bout of aspiration pneumonia. Hospice was very responsive and provided her with pain relief through medications (morphine), laxatives, and stool softeners. The hospice speech therapist came to help us with food preparation for her swallowing issues, and hospice provided home healthcare aides several times a week to assist with bathing and personal care. Hospice would have improved Eileen's quality of life immensely had I called them three to four months sooner.

FROM OUR FAMILIES (continued)

Second: There were several hospice alternatives in our area; fortunately, we selected one that provided support not only for the patient but also for my family and me as well. Hospice made available to us: spiritual counseling, terminal illness literature for my young granddaughters, funeral preparations, grief counselor recommendations, and a bereavement support group, which I joined several months after Eileen's death.

Third: I've heard some people say they feel guilty calling hospice because they feel they are giving up. I did not feel this way nor should anyone else. For example, when you are sick, you don't think twice before you call a doctor to evaluate your condition. The same is true for hospice. I called them to evaluate Eileen's condition. Hospice made the decision as to whether or not Eileen was eligible for their care. This they did by consulting her primary care physician and neurologist, and with a home visit by a hospice nurse.

Fourth: Eileen was very clear that she wanted no heroics near the end life. She was an operating room nurse and put it bluntly to me and our daughters: "It is easy to put the tubes in; it is very difficult to take them out. I do not want the tubes put in!" Hospice ensured her wishes were met. I must admit that it was an emotional experience for me when hospice told me to cancel her future doctors' appointments and that I was to no longer call 911. Rather, I was to call hospice first. However, I realized that these instructions would accomplish what Eileen wanted—there would be no heroics.

I have the highest regard for hospice. They were extremely competent and responsive. They eased Eileen's pain and provided many necessary services for her, my family, and me. My advice—do not hesitate to call.

From Steve Garcias

Probably the best advice I received was to try hospice before we actually needed it. Then, if the first company we used didn't pan out, we would have time to try others.

Hospice brought massages, barrier creams, bathing in bed, and a portable toilet. It was okay. However, we had better luck hiring private home care. We felt it was more personal and less rushed: the care assistant did not have to get to a next appointment. But every hospice is different.

We started this care a year before death.

The only part I still feel in the dark about is pain management in the final days. The tough part for me was pain management. When the patient cannot communicate, it is hard to know if they are truly comfortable.

From Roxi Padrid

First, hospice was a godsend. However, we needed to get over the fear that comes with the label "hospice." Most people, us included, think of hospice as the end (i.e., your loved one is going to die within six months or less of being on hospice). This is not always true. My mom lived for a year and a half off and on hospice.

Second, what many people do not realize is that you may choose to take the person off hospice at any time to treat infections. We did this several times when my mother developed pneumonia. You can re-certify them for hospice after they've been treated. In the end, my mom developed pneumonia, and we took her

off hospice to treat her in the hospital. She did not survive. She was intubated and unable to communicate. After a week-long fight, my brother and I made the gut-wrenching choice to extubate her. Watching my mother suffer, and choosing to extubate her, was the worst time of my life. Looking back, I would not have taken her off hospice and would have let her die at home with the help of drugs to keep her comfortable. We did not know my mother's wishes and so had to guess as to what she wanted. I would advise everyone to have that difficult conversation so that when the time comes, you know you are honoring your loved one's wishes.

Third, hospice provided us with many services, including bi-weekly bath aides, massage therapists, clergy visits (if you want), and a few hours of respite per week.

And last, I agree with Steve Garcias that it depends on the hospice provider as to the quality of care. Obviously, some are better than others, so it is important to interview more than one and to check references or reviews.

From Fran Gardner

Unfortunately, we had a negative experience seeking palliative service. To my surprise, none of the hospices in our area offered palliative last year. Al was being discharged from rehab and was denied hospice because it was important to him to continue therapy. So he was discharged to home health.

End of Life Hospice: We had planned that Al pass at home early on, but as the end unfolded, he was an inpatient in the hospital and was transferred to inpatient hospice. It was a positive experience, where he had 24/7 nursing and physician care, was comfortable, and was pain-free. This gave us the opportunity to focus on our goodbyes.

There are some wonderful hospice facilities that are family supportive. Depending on individual circumstances, a facility may be a better option than home hospice. (I am thinking of the group of spouses that may need to continue working, or PSP patients who don't have the family support at home).



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