Being an Engaged Care Partner:

A Guide for Spouses of People with Lewy Body Dementia

Rosemary Dawson, Jeff Maruna, and Pat Snyder

Edited by Annie Gottlieb and Helen Whitworth

Draft December 2015

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Disclaimer

The medical and health-related information in this Guide is for educational purposes and is general in nature. You should not use it as a substitute for advice from a health care professional. Consult with your spouse's healthcare providers regarding his or her medical condition, treatment, medications, and other needs.

We have made every effort to provide accurate and timely material, but things do change in the healthcare field. Ask questions of healthcare professionals if you have any questions or doubts.

FOR THIS DRAFT VERSION

This Guide has been reviewed and edited several times, but it is undergoing two further reviews:

1. By healthcare professionals (LBD specialists, other doctors (such as hospitalists), nurses, and other ER and hospital staff.
2. By care partners of spouses with Lewy body dementia.

We expect the final revision based on these reviews to be completed by March 1, 2016.

Please look for the final version at

http://www.lbdtools.com/carepartners.html

after March 1, 2016.

Special Request for Readers of this Draft

We are pleased that you have found this Guide and are interested in reading it. This is a draft version that we will revise based on the reviews of healthcare professionals and care partners of spouses with Lewy body dementia.

If you are a healthcare professional, when you have finished reading the Guide, or even if you have read only portions of it, please complete the survey at

https://www.surveymonkey.com/r/Professional-CPG

If you are a care partner for a spouse with LBD, when you have finished reading the Guide, or even if you have read only portions of it, please complete the survey at

https://www.surveymonkey.com/r/CarePartner-CPG

We will use your comments, suggestions, and other feedback to revise the Guide. Your opinions matter to us and will help us to improve this resource.

Please complete the survey by February 1, 2016.

Thank you,

Rosemary, Jeff, and Pat

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Acknowledgements

We offer our heartfelt thanks to the people who helped with this project. Members of the LBD Caring Spouses online support group have provided inspiration and contributed ideas. Our hope is that current and future Caring Spouses and other LBD care partners will benefit from this Guide.

Many current and former care partners reviewed sections of the Guide and provided valuable feedback that was used to revise each section.

Annie Gottlieb and Helen Buell Whitworth used their copy editing skills to fine tune the writing as well as to contribute content from their extensive knowledge of LBD from the care partner's perspective.

Alyce Dawson worked her magic in formatting the document and, as usual, provided ongoing support.

Special thanks to the care partners who shared their stories about their roles as engaged care partners to their spouses with LBD: Millie Seader (Alan), Karen Long (Bill), Jeff Maruna (Kathy), Pat Snyder (John), Rosemary Dawson (Lilburn), Randi Pisapia (Glynne), Jane Gagle (Burk), Pat Tobie (Don), and Sandra Soon (Douglas).

We recognize and appreciate the time it will take for people to read the draft version and complete the survey. Your efforts will allow us to improve this Guide. Thank you in advance.

Dedication

To our spouses

Lilburn Dawson (1939 – 2014)

Kathy Maruna

John Snyder (1939 – 2015)

And all others who are now or who have been in the grips of Lewy body dementia.

Table of Contents

Introduction

Who This Guide is for

This guide is for ***you*** if your spouse

- has been diagnosed recently with Lewy body dementia (LBD),
- has had LBD for some time or,
- has a diagnosis pending based on symptoms common to LBD.

As a care partner of a spouse with LBD, you face unique challenges and have special needs. Caring for a spouse is different from caring for a parent or other family member. Caring for someone with LBD is different from caring for a person with other progressive terminal illnesses. You face a different set of problems because of the unique characteristics of LBD and your intimate relationship with your spouse. This guide contains information that addresses your special situation.

Other care partners may also find the guide useful:

- family members and others who care for people with LBD
- spouses, family members, and others who care for people who have other diseases, especially progressive terminal illnesses

What This Guide is NOT and What it IS

You can find a lot of useful information on the Internet and in print materials to help you be a good care partner – but, you won't find it all in one place. You would need to locate several or more sites to compile the information you need. You probably don't have a lot of time or energy to search for what you need online, so we have done this work for you.

In this guide, you will ***not*** find

- Five Easy Ways to…
- Top 10 Reasons for…
- Shortcuts to Success…
- Commands, directives, or hard-and-fast rules

Many of the articles on the Web deal with only a small portion of what you need to know about and be able to do to accomplish the tasks of an engaged care partner. This can be frustrating when you need comprehensive information. This guide provides an inclusive discussion of each care partner issue.

This booklet is not about the basics of Lewy body dementia. There are many print and electronic resources that provide excellent information about the causes, risks, symptoms, diagnosis, and treatment of LBD. Some of these are listed in Section 2 on preparing yourself to be an engaged care partner. If you are not familiar with the basics of LBD, read one or more of the suggested resources.

You ***will*** find

- tips, helpful hints, advice, and suggestions gathered from 11 years of discussions among care partners of spouses with LBD
- best practices, guidelines, and strategies gleaned from research articles for professionals and information for care partners
- findings from a survey of 165 care partners of spouses with LBD
- personal stories from care partners of spouses with LBD
- links to reliable resources related to being a care partner for a spouse with LBD

This is not a book to read like a novel or non-fiction story. We suggest that you do the following:

1. Read the Table of Contents to get an idea of what is in the guide.
2. Skim each section to see what is covered.
3. Identify areas where you already have some to a great deal of knowledge and those where you need to learn a lot.

4. Concentrate on the sections that suggest actions to take right away depending on your situation, such as creating an LBD portfolio.
5. Anticipate your needs and read the related sections so that you are prepared when the needs arise (e.g., a trip to the emergency room).

Conventions throughout the Guide

Personal anecdotes

You are not alone on your Lewy journey. Many others are facing or have faced what you are facing now. The care partner stories at the beginning of each section illustrate one or more of the ideas discussed in that section.

Links to Internet Resources

Most sections contain links to Internet sites where you can find additional resources. If you are reading online, just click on the link to go to the site. If you are reading a print copy, either go to the Guide online to click on the links, or copy the URL into your browser.

Switch between male and female spouses

We don’t know if your spouse is a man or a woman, so we don’t know how to refer to him or her – and we don’t want to make you read *him or her* throughout the Guide. To make it easier for you to read, one section will refer to the spouse as a man, the next section will refer to the spouse as a woman, and so on.

Survey results

During the fall of 2015, 165 care partners of spouses with LBD completed an online survey, Care Partners as Members of Their LBD Spouse’s Health Care Team, which focused on the topics in this guide. Because the people who completed the survey may be different from a random sample of care partners, we look at the results as points of discussion, not scientific findings. The information in the blue text boxes highlights areas discussed in each section of the Guide.

From the Survey

- 96% of the care partners were women.
- 96% of the care partners were white; 93% of the spouses with LBD were white.
- 92% live in the U.S.; 6% in Canada; and 2% in England.
- Almost all were between 56 and 75 years old, with about equal distribution for 56-60, 61-65, 66-70, and 71-75. 6% were younger than 56, and 9% were over 75.
- Most of the spouses with LBD were between 66 and 80. 12% were between 61 and 65, 7% were between 51 and 50, and 10% were between 81 and 85.
- The time since diagnosis with LBD was distributed rather proportionately between six months and more than five years.
- Most care partners had been married to their spouses with LBD between 32 and 60 years.
- Almost all of the care partners and their spouses were well-educated. 35% of the care partners and 26% of their spouses held undergraduate, four-year degrees. 30% of the care partners and 39% of their spouses held graduate degrees.
- 70% of the care partners were not employed; 24% worked full or part time outside the home; and 6% worked full or part time from home.
- Most care partners were in good (23%), very good (43%), or excellent health (20%). 11% were in fair health, and 3% were in poor health.

Word cloud summaries

At the end of each section, you will see a word cloud like the one at the end of this introduction. Each one contains key words and phrases from the section to help you remember important ideas.

Disclaimer

The medical and health-related information in this Guide is for educational purposes and is general in nature. You should not use it as a substitute for advice from a health care professional. Consult with your spouse’s healthcare providers regarding his or her medical condition, treatment, medications, and other needs.

We have made every effort to provide accurate and timely material, but things do change in the healthcare field. Ask questions of healthcare professionals if you have any questions or doubts.

1. What Does it Mean to Be an Engaged Care Partner?

I went with my husband to every doctor's appointment and soon learned that he wasn't always completely honest with his physicians. I decided I had to be more active in his care. I started a journal. Before a doctor's appointment, I would go through my notes and make a list of everything that I felt was important for the doctor to know. I also monitored Alan's medications which was not easy because he had been a pharmacist. I noted any possible side effects when medications or their dosages were changed. In addition, I made sure that he continued to have a social life with both friends and family. One of the most difficult parts of being a care partner is to remember that your loved one is still there inside. One day, I was encouraging Alan to drink a little more, and his response was, "For a kiss." I knew for sure that he was still there.

Millie and Alan

Perhaps your spouse has been diagnosed with Lewy body dementia (LBD), or maybe he has many LBD symptoms and you are waiting for a diagnosis. If so, your world has already changed in many ways, and you can expect more changes to come. You feel uncertainties, concerns, fears, frustrations, anger, loss, and more. You want to do all that you can to provide your spouse with physical, psychological, emotional, and spiritual support. You want your loved one to get the best possible medical care. You have become your spouse's care partner.

Caregiver or Care Partner?

Being a care partner is different from being a caregiver. Caregiving implies a one-way relationship, with one person giving and the other person receiving. Care partnering is a two-way relationship. Your spouse contributes, to the extent possible, to everyday activities. He continues to share his love and enduring strengths, gifts, and talents with you. You recognize that he still has a wide range of emotions, needs, and preferences. Early on, he contributes to decision making. As that ability fades, you still share joy, emotional intimacy, and personal growth.

As a care partner of a spouse with LBD, you face unique challenges and have special needs. Caring for a spouse is different from caring for a parent or other family member. Caring for someone with LBD is different from caring for a person with other progressive terminal illnesses. You face a different set of problems because of the unique characteristics of LBD and your intimate relationship with your spouse.

You see your spouse as an entire person, not just as a patient with a set of symptoms. For as long as your spouse is able, you encourage him to

- make as many decisions as possible
- express personal goals
- do the things he enjoys doing.

Your spouse's active engagement is a cornerstone of his person-centered, relationship-based care.

As care partner, you are a vital, central member of your spouse's healthcare team. The team can have many members at different times. Besides you, a few will be crucial throughout your journey, especially the doctor responsible for treating your spouse's LBD symptoms. Section 4 provides guidance on locating an LBD specialist who is right for your spouse and you. Your spouse may continue to see a primary care physician (PCP), or the specialist may take over that role.

Among others on your team are doctors specializing in any other illnesses your spouse may have. He may also see physical, speech, and occupational therapists. To provide the best care possible, this whole team needs to work together. Making this happen is often the care partner's job. Being engaged helps you to do this.

Being an Engaged Care Partner

You probably remember when people thought that the doctor always knew best – as with the ’50s TV drama *Marcus Welby, M.D.* Doctors made decisions without consulting patients or their families. Patients and their families rarely, if ever, questioned the treatment or medication; they just tried to follow the doctor’s orders. When they did speak up, they frequently felt that their doctors didn’t listen. Thus, all too often, doctors did not have important information about their patients’ symptoms and lives. Recently, doctors realized that they were missing opportunities to provide better care.

Now, there is a more patient/person- and family-centered approach to care, with a focus on relationships and active engagement. A partnership between healthcare providers, patients, and families incorporates

- respect and dignity
- information sharing
- effective communication
- empathy
- participation
- empowerment
- collaboration

Your spouse is part of this partnership to the extent that his abilities allow. Gradually, you will take on more responsibilities, including performing the engagement behaviors that help him to benefit in the best way from the available healthcare.

Specific Engagement Behaviors for Care Partners

The Center for Advancing Health developed the Engagement Behavior Framework. It is “a comprehensive list of measurable actions individuals and/or their caregivers must perform in order to maximally benefit from the healthcare available to them" (Center for Advancing Health, 2010). These are actions patients can take to participate effectively in their care. As dementia limits patients' ability to perform many of these tasks, their care partners must assume responsibility. The Center for Advancing Health lists ten types of tasks with specific behaviors for each type of task. See Table 1 below. Later sections of this guide provide advice on how to perform many of these behaviors.

Table 1 **Center for Advancing Health** **Engagement Behavior Framework**
Find Good Healthcare
Find provider(s) who meet personal criteria (e.g., performance, cost, geographic access, personal style), will take new patients, and accept personal insurance.
Use all available comparative performance information (including cost data) to identify prospective providers.
Establish a relationship with a healthcare professional or group.
Use all available comparative performance information (including cost data) to identify prospective healthcare facilities.
Seek and use the appropriate healthcare setting when professional attention is required.
Communicate with Healthcare Professionals
Prepare in advance of appointments a list of questions and issues for discussion with the healthcare professional.
Bring a list of all current medications (including supplements and alternative products) and be prepared to discuss their benefits and side effects.
Report accurately on the history and current status of physical and mental symptoms.
Ask questions when any explanations or next steps are not clear and express any concerns about recommendations or care experiences.
Organize Healthcare
Make appointments; inquire about no-show policies; arrive on time.
Assess whether the facility can accommodate unique needs (e.g., physical navigation, hearing or visual impairment, translation services), and arrange for assistance.
Bring documentation of health insurance coverage.
Bring another person to assist if the patient is frail, confused, unable to move around, or unable to remember the conversation with the provider.
Bring a summary of medical history, current health status, and recent test results to visits as appropriate.
Ensure that relevant medical information is conveyed between providers and institutions.
Obtain all test results and appointment records and maintain personal health record.
Pay for Healthcare

Compare coverage options; match to personal values, needs and preferences; and select coverage.
Gather and submit relevant eligibility documentation if applying for or seeking to maintain public insurance (e.g., Medicaid, Medicare, SCHIP); compare coverage options if applicable; match to personal values, needs, and preferences; and select affordable, quality coverage.
Before seeking treatment, ascertain benefit coverage restrictions or incentives such as mental health benefits limitations, pre-certification requirements, access restrictions to specialists or adjunct health providers, and variables in co-pays for specific types of care or providers.
Maintain or adjust coverage in the event of changes in employment, eligibility or family status (i.e., job change, marriage, divorce, birth of child).
Maintain all receipts for drugs, devices and services; submit any documentation of services or payments upon request or as needed for third-party payers (e.g., private insurance, medical/flexible health savings accounts or public payers).
Make Good Treatment Decisions
Gather additional expert opinions on any serious diagnosis prior to beginning any course of treatment.
Ask about the evidence for the efficacy (risks and benefits) of recommended treatment options.
Evaluate treatment options.
Negotiate a treatment plan with the provider(s).
Participate in Treatment
Learn about any newly prescribed medications and devices, including possible side effects or interactions with existing medications and devices.
Fill or refill prescriptions on time, monitor medication effectiveness, and consult with prescribing clinician when discontinuing use.
Maintain devices.
Evaluate and receive recommended diagnostic and follow-up tests in discussion with healthcare providers.
Monitor symptoms and conditions (e.g., for diabetes — monitor glucose regularly, check feet; for depression — medication and/or counseling and monitor symptoms; for hypertension — measure blood pressure regularly, maintain blood pressure diary). Watch for danger signs that require urgent attention.
Promote Health
Set and act on priorities for changing behavior to optimize health and prevent disease.
Identify and secure services that support changing behavior to maximize health and functioning and maintain those changes over time.
Manage symptoms by following treatment plans, including diet, exercise and substance use agreed upon by them and their provider.
Get Preventive Healthcare
Evaluate recommended screening tests in discussion with healthcare provider.

Act on referrals for early detection screenings (e.g., breast cancer, colon cancer), and follow up on positive findings.
Get recommended vaccines and participate in community-offered screening/wellness activities as appropriate.
Plan for the End of Life
Complete advance directives and medical power of attorney; file with personal records.
Discuss directives with family physician and other healthcare providers, appropriate family, and/or significant others.
Review documents annually; update and distribute as needed.
Seek Health Knowledge
Assess personal risks for poor health, disease and injury, and seek opportunities to increase knowledge about health and disease prevention.
If diagnosed with a chronic disease, understand the condition(s), the risks and benefits of treatment options and personal behavior change(s) by seeking opportunities to improve health/disease knowledge.
Know personal health targets (e.g., target blood pressure) and what to do to meet them.
A New Definition of Patient Engagement: What Is Engagement and Why Is It Important?, Health, Center for Advancing Health: Center for Advancing Health, Washington, D.C., (2010). http://www.cfah.org/file/CFAH_Engagement_Behavior_Framework_current.pdf

Characteristics of an Engaged Care Partner

As you looked at the list of engagement behaviors in Table 1, you probably saw some that you know you can do and/or have done before. There are some that might challenge you and your current abilities, but these are things you can learn. An engaged care partner possesses the traits and abilities outlined below:

A desire to be an active participant in your spouse's healthcare team. You need to want to collaborate with your spouse's LBD doctor and others who care for him. This may be quite different from the relationships you have had in the past. You may have been comfortable with the doctor making most, if not all, of the decisions without discussing them with you. You also need to have a strong personal commitment to your spouse. It takes significant effort to be an engaged care partner.

A certain degree of health literacy. To engage effectively in shared decision making, you need to know some basics about

- health
- how the body works

- the fundamentals of medications
- the function of the healthcare system
- financial and legal aspects of healthcare

A willingness to learn. You may need to learn more of the basics. You also need to learn about LBD, its symptoms, treatments, medications, and more. This takes a readiness to acquire new learning.

Resources to help you learn and perform the engagement tasks. It can be overwhelming to anticipate all that needs to be done. It helps to know that there are resources to assist you with each task. This guide identifies many resources to help to take the actions of an engaged care partner.

Your own good physical and emotional health. It is hard work to be a care partner for a spouse with LBD. You need to take care of your own health:

- monitor any physical conditions
- follow your own healthcare plan
- try to get sufficient rest
- eat as healthily as possible

Being a care partner is also emotionally taxing. You need to:

- reduce stress
- take regular respite breaks
- have an interest in something besides care partnering
- seek avenues of emotional support (family, friends, church organizations, support groups, counselors, or therapists)

What You Can do to be an Engaged Care Partner

The empowering strategies in this guide will help you to be an actively engaged member of your spouse's healthcare team. These strategies can assist you with

- preparing to be an engaged care partner
- creating an LBD portfolio
- finding a specialist to treat your spouse's LBD symptoms

- developing successful relationships with the LBD specialist and other members of your spouse's healthcare team
- being an engaged care partner before, during, and after visits to the LBD specialist
- being an engaged care partner before, during, and after trips to the emergency room
- being an engaged care partner before, during, and after hospitalizations
- handling problems and conflicts with the LBD specialist and other members of your spouse's healthcare team

2. Preparing to Be an Engaged Care Partner

I think it takes a full year for the shock of a diagnosis of LBD to settle in – to get to the point of "I can do this" – albeit one day at a time. I am like a thirsty sponge on the LBD Caring Spouses site. With tips from those far advanced in the progression of LBD, I have been able to make many decisions and take actions: get paperwork in order, find an LBD specialist, provide information to some of Bill's doctors who had never heard of LBD, move to a home way more handicap accessible and closer to help, and most recently get ready to do an involved bathroom renovation.

Karen and Bill

You have four essential choices to make to prepare yourself to be an engaged care partner. These approaches will help you in that role for the duration of your LBD journey:

- Be positive
- Be proactive
- Be perceptive
- Be persistent

Be positive.

After your spouse's diagnosis of LBD, you are likely overwhelmed with negative emotions. These emotions are your first hurdle to overcome, and they tend to be ongoing. Therefore, a commitment to use positive choices to overcome negative feelings will serve you well throughout your time as an LBD care partner.

It might be helpful for you to think of yourself as in a war with LBD. Although your enemy is formidable, you can still win significant battles along the way that will make the overall experience of LBD less damaging to both of your lives. You will find victory and empowerment in winning those battles. Using a positive attitude to overcome a negative situation is not a denial of the difficult situation; rather it is a conscious effort on your part to override its impact. It is psychological and emotional warfare for a good purpose. You are preserving personhood for your spouse and yourself. In doing so, you may find that this is your finest hour.

There are a number of ways to address this choice of being positive. It takes self-discipline and commitment to fight back an enemy that is trying to steal precious moments from your lives. It often involves doing the opposite of what you are feeling in the moment. So first, identify that negative feeling. Then choose to go in another direction. For example:

When you feel:	Then choose to:
• Sad	Spend time with a friend who makes you laugh.
• Empty	Make a list of three things for which you are grateful.
• Anxious	Use lavender oil for its calming effect on both of you.
• Angry	Take deep breaths to calm yourself.
• Fearful of the future	Focus on what is happening in this moment.
• Unhappy	Do something you both enjoy.

These kinds of choices may feel simplistic and artificial when you first start to practice them. Over time, you will feel the benefit of not allowing the negative emotions to swamp you, keeping you in a slump of inactivity and helplessness. You will begin to feel empowered and purposeful in your role. Then you will realize that your positive choices have a profound effect on your spouse's experience of LBD.

Be proactive.

Being proactive means that you take action and not just react to what happens. Being proactive is an ongoing requirement. As you begin to assume your role, these actions will empower you:

- Learn about LBD symptoms.
- Learn about treatments for LBD symptoms.
- Learn about non-pharmacological (non-drug) interventions for LBD.
- Learn to identify the specific triggers that affect your spouse's experience of LBD.
- Connect with other LBD care partners to continue strengthening yourself.

When you and your spouse received the diagnosis of LBD, you may have received some printed materials that defined LBD and directed you to some helpful resources available in your community. However, you need to seek out more in-depth knowledge to fulfill your role as the care partner.

From the Survey

Which of the following has your spouse's DLB doctor provided for you and/or your spouse? (Check all that apply).

	Percent
Printed educational material about DLB	32.0%
Links to online information about DLB	27.2%
Information about home health care	16.5%
Information about adult day care	6.8%
Information about out-of-home placement	4.9%
Information about palliative care	7.8%
Information about hospice care	10.7%
Information about organizations that might help you as a care partner	26.2%
Information about support groups	31.1%
Caregiving tips accumulated from the experience of other DLB patients the doctor has treated	12.6%
None of the above	35.9%

Do not overwhelm yourself in the beginning. Learn about the basics and gradually add more knowledge. It is important to get information from reliable sources. Use only trusted print and non-print resources. Look at the websites of government agencies, universities, hospitals, and associations devoted to LBD and related diseases. Find medical journals, articles, and books written by LBD experts.

The following Internet sites will provide some of the most reliable information to get you started in educating yourself about LBD:

- http://www.lbda.org -- This is your first place to start. The Lewy Body Dementia Association is an online resource that provides extensive information about LBD, such as the examples below:
- *Lewy Body Dementia: Information for Patients, Families, and Professionals* http://www.lbda.org/sites/default/files/lewybodydementia-final_11-6-13.pdf
- A checklist of LBD symptoms http://www.lbda.org/content/symptoms
- A glossary of medications that have an impact on LBD includes drugs to avoid or use with caution. http://www.lbda.org/sites/default/files/medication-glossary.pdf
- A medical alert card to use with physicians and ER staff http://www.lbda.org/sites/default/files/lbda-wallet-card.pdf
- Medications and non-drug treatments for LBD http://www.lbda.org/content/therapeutics
- The Mayo Clinic does research and treats LBD patients. This site gives you a variety of information about LBD ranging from symptoms to diagnostic tests to treatment options. http://www.mayoclinic.org/diseases-conditions/lewy-body-dementia/basics/definition/con-20025038

You can learn a lot from books about LBD. Here are some excellent books to get you started. You can find these at Amazon.com:

- *Treasures in the Darkness* (Pat Snyder) is about enhancing and extending the early stage of LBD.

- *A Caregiver's Guide to Lewy Body Dementia* (Helen Buell Whitworth and James Whitworth)
- *Managing Cognitive Issues in Parkinson's & Lewy Body Dementia* (Helen Buell Whitworth and James Whitworth)
- A reliable list of other books is at the LBDA website.
- http://www.lbda.org/category/4114/books-on-lbd-and-dementia-caregiving.htm.

Teepa Snow has a series of excellent videos about managing dementia. "Lewy Body Dementia - What Everyone Needs To Know" is specific to LBD. https://dementiacareacademy.com/show_program/149/

Connecting with other LBD care partners helps you educate yourself as well as meet your emotional and social needs. Finding a good support group, either in your community or online, can serve as a resource on many levels. To find a support group near you, check the directory of Local LBD Support Groups on the LBDA website at http://www.lbda.org/content/local-lbd-support-groups.

Online support groups that you may find helpful include:

- LBD Caring Spouses Group
  https://groups.yahoo.com/group/LBD_caringspouses/

  LBD Caring Spouses is a closed online support group for spouses of LBD patients. When you apply to join, identify yourself as the spouse of a person with LBD. Your posts are private and available only to members for reading and responding. The site includes many resources in Files and Links. The authors of this guide are moderators on this forum.

- The Lewy Body Dementia Association forum
  http://www.lbda.org/phpbbforum
- The LBDA forum is for anyone who is caring for a person with LBD. There are sections where you can read about and discuss a number of topics. You apply to join. On this forum, anyone can read your posts.

Some people enjoy Facebook groups for LBD caregivers. These groups tend to be large, and information varies in terms of reliability.

There are blogs about LBD that you may find helpful. Two good options are:

- The Lewy Body Roller Coaster at http://lewybodydementia.blogspot.com/
- Lewy Warriors: Caregivers Helping Caregivers at https://lewywarriors.wordpress.com/

Be perceptive.

As you prepare to become an engaged care partner, be sensitive to the emotional and psychological effects that LBD can have on you and your family. If left unaddressed, these feelings can have devastating consequences that make your LBD journey much more difficult. LBD is likely to magnify any pre-illness emotional and interpersonal issues. Therefore, it is important to identify those issues clearly and learn how to manage them better. Doing this could provide significantly better outcomes for you and your spouse. Consider including a counselor as a member of your healthcare team to help you address:

- Communication issues within the marriage
- Communication issues within the family and among significant friends
- Relationship dynamics
- Pre-illness issues that can affect how you manage symptoms of LBD
- Forgiveness of past hurts
- Learning to roll with the punches if personality changes happen in your spouse

A second element of being perceptive is to be sensitive to your spouse's LBD symptoms, so that you can observe and record changes in physical, psychological, and behavioral symptoms. You see your spouse every day, unlike doctors who see her only for a short time during office visits. Report these changes to the LBD specialist and work together to find solutions. Sometimes changes in medicine can bring about an improvement of symptoms. At other times, non-drug choices can address these issues.

The third element of being perceptive is to identify the specific triggers that have a negative effect on how your spouse experiences LBD. This is where many non-drug interventions can have huge positive outcomes for living daily with LBD. Examples of simple changes with big results may be:

- Softening the light in the room
- Using oils like lavender to calm agitation
- Playing favorite music
- Having only one person speak at a time while in the room
- Explaining what you are about to do before you begin to do it

These may seem like small things, but they can make a big difference in your spouse's disease experience. You must be alert and perceptive to see what triggers agitation or frustration in your spouse. Then you can communicate with key individuals who interact with your spouse to let them know how those things must change to make the best care choices to prevent agitation or other behavioral responses.

Be persistent.

Being a care partner for your spouse with LBD is a long-term commitment. It is a marathon, not a sprint.

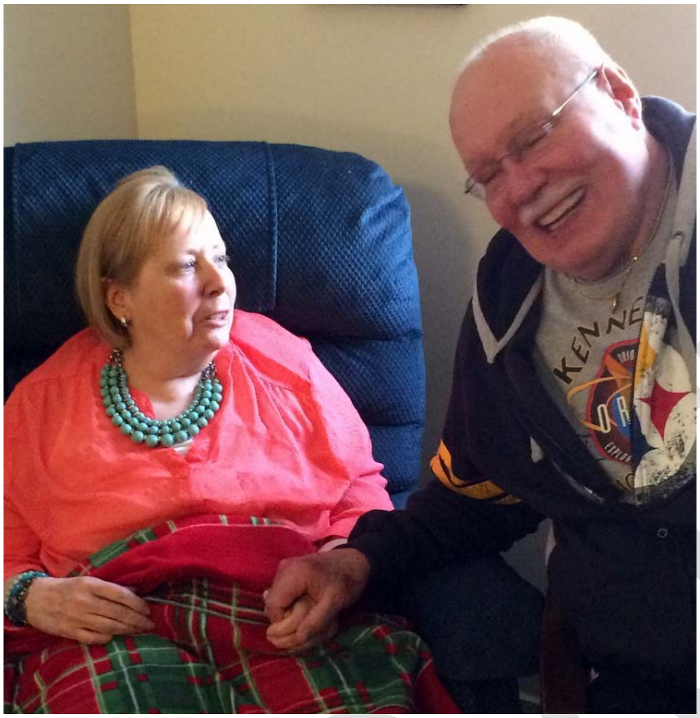
The Lewy roller coaster, a coined term, describes the LBD experience due to the ups and downs in cognitive, physical, behavioral, and psychological symptoms. Your choice to be positive, proactive, and perceptive must be of a continuing, ongoing nature. You need to persist through these fluctuations as your spouse progressively declines. It is a daily choice.

As new symptoms emerge over time, you need to learn more about LBD and stay up-to-date about research and treatments that could be helpful. As care for your spouse continues, you will monitor disease symptoms daily. At times, you may question the efficacy of an intervention. Is it working or is it simply a manifestation of the fluctuations of the disease? This is a typical question for you to ask in your role as LBD care partner. Sometimes you will use your intuition correctly and work with the LBD specialist to change course. Other times you may not discover the answer. That is also typical, so do not blame yourself at these times.

You also monitor those who are involved in your spouse's treatment and support. Part of your role is to teach any new person on her healthcare team about her expression of LBD and how best to approach the situations that arise in her care. You deal with significant family members and friends who encounter her; you need to help them learn about LBD, too. All these things involve a consistent approach on your part.

Your steadfast persistence will pay off in a gentler LBD journey for you and your spouse. This is one of those places in life where you clearly make a difference. It is not easy, but it is doable – and it is worth it.

3. Creating an LBD Portfolio



I found that logging my daily observations on a planning calendar was a valuable tool to track the progress of my wife's LBD symptoms. Fatigue and 24/7 contact with Kathy would often blur my memory and judgment. When I could no longer care for her safely at home, I experienced a tug between my head and my heart. I looked over my observations of the previous five months and saw the clear pattern of increasing falls, sundowning, excessive daytime sleepiness, jerks, freezing, and difficulty in transfers. While the decision to move her to a dementia care facility was heart wrenching, I took comfort in having made the decision supported by my thorough documentation of her symptoms. Jeff and Kathy

When you go with your spouse to the doctor’s office, hospital, or emergency room (ER), you need to share a lot of information. Create an LBD portfolio to collect information about your spouse so that it is all in one place, where and when you need it. This organized portfolio allows you to provide information quickly and accurately. You need some of this information immediately as you start your journey as an engaged care partner, so do not wait to get started on it.

A well-designed and maintained LBD portfolio

- Simplifies the many requests for the same information.
- Helps prevent medical errors.
- Improves communication with multiple doctors across multiple healthcare systems.
- Allows you to provide consistent information across all medical settings.

Portfolio Format

You may want to use a paper-based system with a loose-leaf binder, a portable filing case, a small brief case, or a tote bag. Select something that holds all of the information and documents in an organized manner. Keep it in a convenient place so that you can grab it when you go to the doctor's office, ER, or hospital.

Current technology gives you many choices to collect and maintain medical information. You can keep information in a digital, electronic format on your computer, laptop, tablet, or smartphone; or you can maintain paper copies that you print from your computer. What you do depends on your comfort level with technology. You also need special devices, such as a smartphone, for many applications. Many available applications (apps) require particular devices, such as a smartphone.

Look at several of the possible apps and answer these questions.

- How easy is it to use?
- How accurate is it?
- Is it easy to update and revise information?
- How can you share the digital information with healthcare providers?
- Can you transfer the information to another device?
- Can you print the data from the application?

A Family Caregiver's Guide to Electronic Organizers, Monitors, Sensors, and Apps can help you understand how technology might help you collect and manage your spouse's medical information. It has five sections:

- Coordinating healthcare and support services
- Organizing health information with electronic health records, patient portals, and personal health records
- Communicating with family and friends, and scheduling help
- Personal Emergency Response Systems (PERS)
- Home monitoring systems.

The guide includes a glossary and ways to learn more about technology. It is also available in *Spanish, Russian, and Chinese.*
*S*ee http://www.nextstepincare.org/Caregiver_Home/Technology/

Here is a review of 12 digital applications, most of which are free. “Maintain your health and mind with these 12 medical apps” at http://www.digitaltrends.com/mobile/best-medical-apps/

This article reviews “4 Top Apps for Organizing Your Medical Records” at http://www.healthedeals.com/articles/4-top-apps-for-organizing-your-medical-records

Microsoft has a free service called HealthVault to manage personal health information, including prescriptions, allergies, personal medical history, family medical history, current health conditions, summaries of medical visits, test results, and more. You can access the information from almost any kind of electronic device and transfer data easily, too. Learn more at https://www.healthvault.com/us/en.

Consider the following apps described and reviewed in “Best Family Health Apps” at http://appcrawlr.com/ios-apps/best-apps-family-s-health

Choose a format and application that allow you to store and maintain the information and forms described below. The best LBD portfolio is the one that works best for you. Use trial and error to modify the portfolio to meet your needs.

From the Survey

Most of the care partners have a folder, binder, or other container with the information they need to coordinate their spouses’ care? (LBD portfolio)

No	31.7%
Yes	68.3%

However, most do not have all of the contents described below. (See next Survey text box.)

Contents of the LBD Portfolio

You probably already have a lot of the information that goes into an LBD portfolio; you just need to find it and put it in one place. Some of the items listed below are more important than others. You can make the portfolio suit your needs now and add to it as new needs emerge. You need some of these items for the first appointment with your spouse's LBD specialist. Don't be overwhelmed by the task; do a little as you have the time.

Your spouse's personal information.

- full name and any aliases
- date of birth, birthplace, race, ethnicity, and sex
- complete address, phone number(s), e-mail address, and other contact information
- whom to contact in case of an emergency (name, relationship, and contact information)
- your complete information as the spouse (name, date of birth, contact information, and employment information)
- Social Security number and the number of a government-issued photo identification card. *File photocopies of these documents in the portfolio.*

Contact information: Include names, addresses, phone numbers, e-mail addresses, and fax numbers for the following (as applicable):

- doctors
- pharmacist
- other service providers
- local emergency responders
- clergy members
- emergency contacts
- family and friends with whom you may want to share information
- hospice agency
- funeral home
- brain donation contact

Health, Medical, and Hospital Insurance Information.

- names of your spouse’s insurance providers (Medicare, Medicaid, group or individual plans)
- File photocopies of health insurance cards in the portfolio. Be sure that the cards have all of the contact information you need to get information about plan coverage or answers to questions.
- If not, add that information to the portfolio (policy numbers, phone numbers, points of contact, e-mail address, mailing address, etc.).

Drug benefit information. Include a copy of your spouse’s pharmacy benefit card (e.g., Medicare Part D) and contact information. Add other benefit-related information such as for electronic prescribing and drug formulary.

Medical History**.** Your spouse’s doctors need his complete medical history. The medical history helps them provide the best care. Include the following:

- Past medical conditions and diagnoses with dates
- Physicians involved in treatment with contact information
- Prior surgeries and procedures including outcomes and any complications (e.g., post-op nausea, vomiting, delirium, difficulty with pain control, etc.)
- Prior hospital discharge instructions if available
- Blood type
- Up-to-date information with dates about inoculations, tests, procedures, or health screenings
- Lifestyle habits such as smoking, drinking, exercise, etc.

Family Health History. Include a record of illnesses and medical conditions affecting your spouse’s family members. Include at a minimum his father, mother, and siblings. If you have information about other family members, include it.

"My Family Health Portrait" is an Internet-based tool that makes it easy for you to record a family health history. The tool is easy to access on the web and simple to fill out. You can share the information online or print it.
See http://www.hhs.gov/familyhistory/portrait/

Medication Record**.** Maintaining an accurate record of medications helps to ensure that your spouse is taking safe medications for the maximum benefit. The chances are that doctors other than the LBD specialist are treating him, and they all need to know all of the medications he is taking. You want to avoid polypharmacy – taking too many medications – and be sure that he is not taking drugs that can cause LBD symptoms or make them worse.

Include the following:

- all currently prescribed medications, herbal and nutritional supplements, and over-the-counter drugs
- discontinued and poorly tolerated medications
- all drug and food allergies
- the brand name for each drug, with its generic name in parenthesis; for example, Exelon (rivastigmine) or Namenda (memantine). This avoids any confusion between similar sounding drug names, such as between Celexa (citalopram) and Celebrex (celecoxib). Often, medical technicians record medication data, and they may not be familiar with the medications your spouse is taking.
- dosage, strength, frequency, prescriber, condition or reason for the drug, date started, date stopped, reaction or ability to tolerate, and notable side effects. Record and update this information for each prescription, supplement, and over-the-counter drug.

AARP has a medications record form that you can download as a Word document and complete on your computer. See http://www.aarp.org/health/drugs-supplements/info-2007/my_personal_medication_record.html

Medical Records**.** Medical records are reports from doctors and labs where your spouse has had testing or procedures done. These reports give his doctors a full picture of his health history. The doctors are able to compare old results with new results.

You may have some of these records already. To get other records, contact the doctor or lab. You will need to complete an “Authorization for Release of Medical Information.”

If your spouse receives care within the same hospital system, all of the doctors in that system may have access to the information via an electronic medical record (EMR) system.

Some medical records are on CDs or DVDs (e.g., X-rays or MRIs). Many specialists prefer to review original results rather than read the interpretation of another physician. Ask to have copies of CDs or DVDs made to include in the LBD portfolio. For any future tests, ask for a copy of the CD or DVD at the time of the test.

You can obtain copies of lab reports and other test results from the ordering physician. Your spouse’s doctor or hospital system may have a patient Internet portal, such as MyChart where you can access and print lab tests, office visit summaries, and other medical records.

Legal Documents**.** You want to have legal documents in place before you need them. Legal aspects of being a care partner need not become complicated or intimidating. These documents require your spouse’s informed consent, and witnesses must verify that he is competent and of sound mind. LBD affects cognitive ability, so it is best to complete these documents as early in the course of the disease as you can. An eldercare attorney can prepare these. You may also be able to create them yourself depending on the requirements of your state.

Medical Power of Attorney (MPOA). A medical power of attorney (MPOA), also known as a healthcare power of attorney HCPOA), permits you to act on behalf of your spouse for all medical purposes. As the proxy, you can make decisions and access information necessary to support his well-being.

If you do not yet have an MPOA, get one as soon as possible. You need an MPOA to be an engaged care partner. As with any legal document, your spouse must be competent to sign it. He must understand and agree to it. In most states, two witnesses must confirm your spouse's identity and the fact that he is competent at the time of the signing.

You can find a typical MPOA at the American Bar Association website. *Giving Someone a Power of Attorney for Your Health: A Guide with an Easy-to-Use, Legal Form for All Adults* provides information about different laws in various states and sample documents.

http://www.americanbar.org/content/dam/aba/administrative/law_aging/2011/2011_aging_hcdec_univhcpaform_4_2012_v2.authcheckdam.pdf

Advance Directive/Living Will. Some states use the term *advance directive*; others use *living will*. This document outlines your spouse's wishes for end-of-life care and is important when he cannot make his wishes known. Without an advance directive in place, you and the doctors may not know your spouse's wishes and may unknowingly ignore his preferences. It can also create challenges for you to implement end-of-life wishes without a written document in place. Your spouse can include as much or as little detail as he would like. Often, a person wants only palliative care and not extraordinary measures when death is imminent. Some people list the specific measures that they do not want (e.g., feeding tube, intubation, CPR, etc.) As with the MPOA, the person must be of sound mind to complete it as verified by witnesses. You can download your state's form at "Download Your State's Advance
Directives" http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289

ADVANCE HEALTH CARE DIRECTIVE

INSTRUCTIONS

Part 1 of this form lets you name another individual as agent to make health care decisions fo
become incapable of making your own decisions, or if you want someone else to make those d
you now even though you are still capable. You may also name an alternate agent to act for yo
choice is not willing, able, or reasonably available to make decisions for you.

Your agent m r supervising health care provider. agent also may not be an
employee re facility or a residential care fa where you are receiving
employ tution where you are receiving ca ss such person is rela
is a co

Unles form, your agent will have the righ
1. Co any care, treatment, service, or proc o maintain, diag
othe al condition.
2. Select n car s and institutions.
3. Approve or disapprove diagnostic te cal procedures, and pro f medicatio
4. Direct the provision, withholding, or withdra tificial nutrition and h and all c
of health care, including cardiopulmonary resu
5. Donate organs or tissues, authorize an autopsy, and isposition of re

However, your agent will not be able to commit you to a me th facility, nt
treatment, psychosurgery, sterilization or abortion for you.

Do Not Resuscitate (DNR) Order. If your spouse had a cardiac arrest or stopped breathing, would he want to be resuscitated? Some people do not want CPR if they are near the end of life or have a terminal illness. A doctor must complete a separate DNR for in the hospital and out of the hospital. You may consider a DNR later in the LBD journey. With an MPOA, you can make this request when your spouse can no longer make his wishes known. Read more about DNRs at https://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000473.htm

From the Survey

Most of the care partners have these three documents in place.

	Percent
Medical Power of Attorney (MPOA)	96.8%
Advance Directive/Living Will	88.4%
Do Not Resuscitate order (DNR)	66.3%

Symptom Observation Log**.** Your spouse's LBD specialist probably spends 15-30 minutes during each visit – not much time to observe and assess symptoms. The doctor needs more information to make a complete and accurate assessment of your spouse's status and identify changes since the last appointment.

You may have seen your spouse be more alert, with improved motor skills and cognition during office visits. This temporary period of enhanced performance is *showtime*, during which he appears less impaired than what you observe at home. This can give the doctor an inaccurate view of your spouse's typical behavior.

You provide the LBD specialist with important information by recording your spouse's LBD symptoms in a log or diary. You benefit from symptom tracking, too, because when you spend many hours and days with him, you may not recognize subtle changes. Record changes in memory, cognition, emotions, behavior, movement, breathing, sleep, incontinence, and other issues.

The LBDA offers a Comprehensive Symptom Checklist. Use this checklist as a starting point to identify new LBD symptoms and record changes in the frequency or intensity of existing symptoms. With this information, the LBD specialist can assess your spouse's condition more accurately leading to a better treatment plan. You can find the LBDA checklist at http://www.lbda.org/sites/default/files/2013_comprehensive_lbd_symptom_checklist.pdf

Your spouse probably has other health problems –what doctors call *comorbidities*. He may have hypertension, diabetes, or arthritis. Perhaps, he has cardiac, prostate, or bladder issues. Ask his doctors if you should monitor and record blood pressure (BP), blood glucose, weight, pulse, or other vital signs.

Lewy Body Dementia Materials**.** Some healthcare workers do not know much about LBD. This poses risks, for example, if a doctor prescribes a medication that is dangerous for someone with LBD. Include materials about LBD to educate others and to have on hand as quick references.

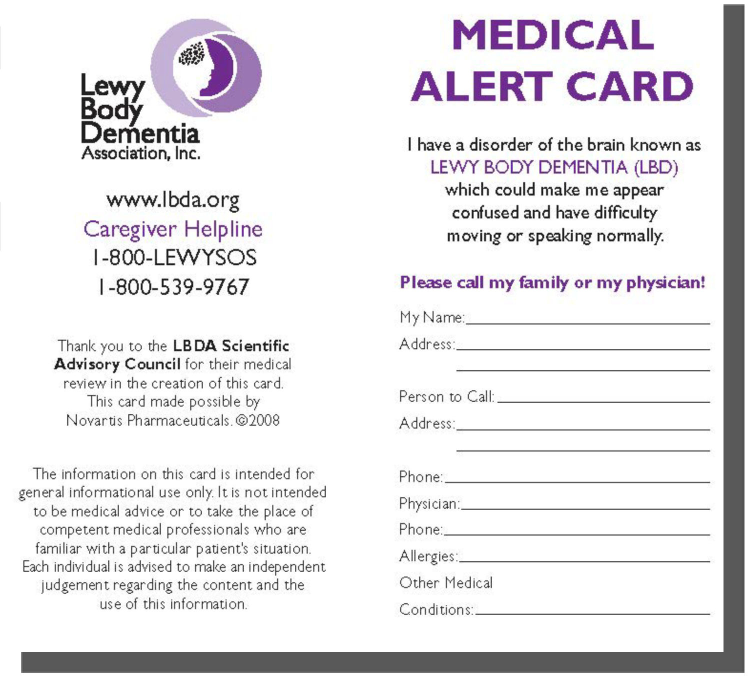
- Printed materials (e.g., fact sheets from the LBDA) for emergency responders, emergency room (ER) staff, and hospital personnel who may be unfamiliar with LBD.
    - LBDA materials especially for doctors: http://www.lbda.org/physicians
    - Lewy Body Dementia: Information for Patients, Families, and Professionals http://www.lbda.org/sites/default/files/lewybodydementia-final_11-6-13.pdf
    - Medication Glossary - A glossary of medications that treat cognitive, motor, mood, or behavioral symptoms. It also includes medications to avoid or use with caution. http://www.lbda.org/sites/default/files/medication-glossary.pdf
    - Medicines and non-pharmacological treatments for LBD http://www.lbda.org/content/therapeutics

- Materials about medications that should be avoided or used with caution
  - Beers Criteria (Medication List): Potentially Inappropriate Medications for the Elderly According to the Revised Beers Criteria (2012)
A 14-page brochure from the American Geriatrics Society
Download at http://www.americangeriatrics.org/files/documents/beers/2012AGSBeersCriteriaCitations.pdf
  - Anticholinergic Cognitive Burden (ACB) Scale
A 1-page chart from the IU Center for Aging Research
Download at http://seniorshealthknowledgenetwork.com/sites/seniorshealthknowledgenetwork.ca/files/ACB_Anticholinergic_Burden_List_.pdf
  - Benzodiazepines: List of Trade Names, Uses and Dosage
At http://www.uatests.com/drug-information/benzodiazepines-list.php
  - List of benzodiazepines
At https://en.wikipedia.org/wiki/List_of_benzodiazepines

  - Alternatives for Medications Listed in the AGS Beers Criteria for Potentially Inappropriate Medication Use in Older Adults
    A 2-page Tip Sheet from the Health in Aging Foundation.
    Download at http://www.healthinaging.org/files/documents/tipsheets/BeersAlternatives_2015.pdf
  - Avoiding Overmedication and Harmful Drug Reactions
    A 2-page Tip Sheet from the Health in Aging Foundation.
    Download at http://www.healthinaging.org/files/documents/tipsheets/Tip.Avoiding_OverMedication.pdf
  - Ten Medications Older Adults Should Avoid or Use with Caution
    A 2-page Tip Sheet from the Health in Aging Foundation.
    Download at http://www.healthinaging.org/files/documents/tipsheets/meds_to_avoid.pdf

- Your spouse's completed LBD Medical Alert Wallet Card

  http://www.lbda.org/sites/default/files/lbda-wallet-card.pdf



Lewy Body Dementia Association, Inc.

www.lbda.org
Caregiver Helpline
1-800-LEWYSOS
1-800-539-9767

Thank you to the **LBDA Scientific Advisory Council** for their medical review in the creation of this card. This card made possible by Novartis Pharmaceuticals. ©2008

The information on this card is intended for general informational use only. It is not intended to be medical advice or to take the place of competent medical professionals who are familiar with a particular patient's situation. Each individual is advised to make an independent judgement regarding the content and the use of this information.

MEDICAL ALERT CARD

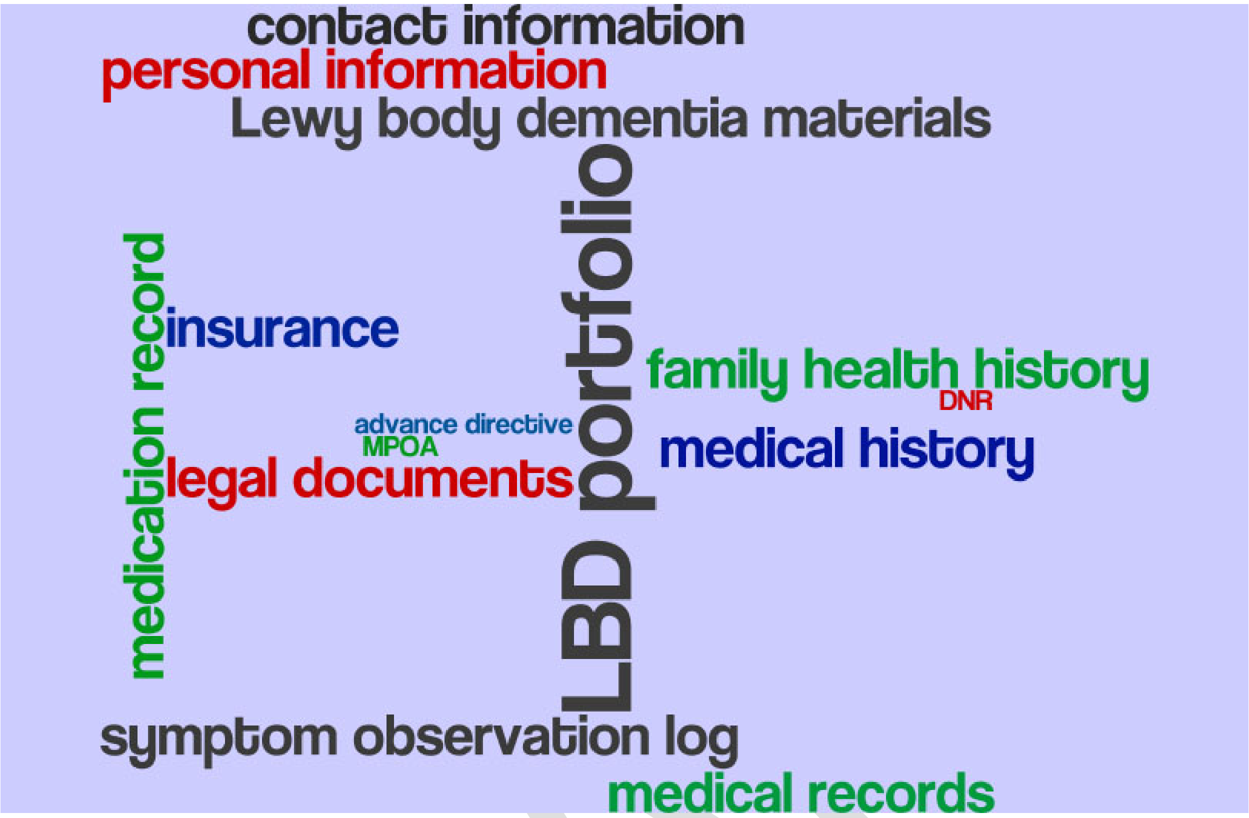
I have a disorder of the brain known as LEWY BODY DEMENTIA (LBD) which could make me appear confused and have difficulty moving or speaking normally.

Please call my family or my physician!

My Name: ____________________
Address: ____________________
____
Person to Call: ____________________
Address: ____________________
____
Phone: ____________________
Physician: ____________________
Phone: ____________________
Allergies: ____________________
Other Medical Conditions: ____________________

From the Survey

Most LBD portfolios don’t have all of the needed contents.	Percent
Names, phone numbers, e-mail addresses, and other ways to contact services, doctors, and others involved in your spouse’s health care	58.2%
Names, phone numbers, e-mail addresses, and other ways to contact people that may need to be communicated with	31.6%
Name, phone and fax numbers, address, etc. for your pharmacy	42.9%
Information about what to do when there is a problem or emergency	34.7%
Copies of medical records from other doctors	38.8%
Contact information and release forms for the LBD doctor to obtain information from other doctors and medical facilities	16.3%
Copy of your medical Power of Attorney (POA)	56.1%
Copy of your spouse’s advance directive/living will	51.0%
Copies of health insurance card(s)	49.0%
Copy of pharmacy plan card	35.7%
Copy of your spouse’s DNR order (do not resuscitate)	39.8%
A list of your spouse’s current and past medical conditions	39.8%
Dates and results of tests, shots, procedures and/or health screenings	31.6%
Information about your spouse’s surgical procedures	20.4%
Information about your spouse’s family’s medical history	11.2%
Up-to-date information about all of your spouse’s current medications	51.0%
Information about your spouse’s allergies to foods and drugs	35.7%
Information about positive and adverse reactions to drugs	30.6%
Log, record, or diary of spouse’s LBD symptoms or LBD symptom checklist	28.6%
Record of your spouse’s vital signs	22.4%
Your spouse’s completed LBD Medical Alert Wallet Card	26.5%
Your spouse’s government issued photo ID	29.6%
Photo & personal information about your spouse	13.3%
Printed materials (e.g., fact sheets from the LBDA)	29.6%


contact information
personal information
Lewy body dementia materials
LBD portfolio
medication record
insurance
family health history
DNR
advance directive
MPOA
legal documents
medical history
symptom observation log
medical records

4. Finding the Right LBD Specialist

On the diagnostic journey, we saw twelve doctors: three primary care physicians, two internists, one endocrinologist, one psychiatrist, one surgeon, one hospitalist, and three neurologists. Our daughter said, “Mom, what if you had not persisted and just stayed with that first neurologist, who gave us no sense of hope at all? Think of where Pops might be today? Other people need to know how important it is to keep looking until you get the right doctor.”

Pat and John

Before you Start

Finding the right doctor to treat your spouse’s LBD symptoms is one of the most important steps in building a person-centered and relationship-based healthcare team. Fortunately, there are many resources available to help you answer the following questions:

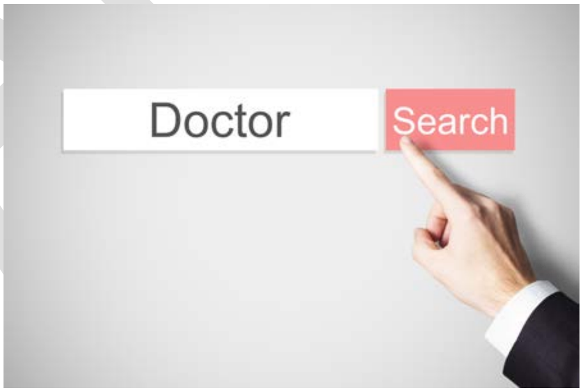
- What do you need to know and think about to make the best choice of an LBD specialist for your spouse and you?
- Where can you go for information about doctors?
- How can you locate doctors in your area?
- What questions should you ask potential doctors?

Most doctors will respect that as the care partner of a spouse with LBD, you are the key decision maker in her care. However, you need to make sure at the beginning of your medical team-building efforts that you have the legal right to speak and act on her behalf.

If you have not already done so, have an attorney create a legal document that secures your role as your spouse's healthcare agent. Such a document gives you access to all of her medical records, allows her doctor to talk to you about her medical issues, and allows you full authority to make decisions and to speak for her. Depending on where you live, this might be called a medical power of attorney (MPOA), a healthcare power of attorney (HCPOA), or a healthcare proxy. For information on MPOAs, see Section 3. Give all healthcare providers a copy of this document to put in your spouse's file. Keep a copy in the LBD portfolio discussed in Section 3.

As you start your team-building efforts, think of yourself as a coach who is putting together just the right team for a season of play. You are the person who decides who is on the team and who is not. In doing so, you gain a sense of empowerment that gives you confidence and helps you overcome apprehensions and fears. You are not helpless here. You can acquire the knowledge and skills to be a proactive decision maker along with your spouse (to the extent that she can participate).

Because the LBD journey is most often a long-term experience, it is critical that you choose an LBD specialist with whom you can work comfortably. It is stressful to try to work with a doctor who does not have sufficient expertise or who is not supportive, compassionate, and understanding of your role as a central member of the care team. Both the quality of your spouse's medical care and the overall LBD experience for you and your spouse depend on your choice of the LBD specialist.



Your Spouse's Primary Care Physician (PCP)

Your spouse is likely to need more than one doctor. In an ideal situation, one doctor, often the primary care physician (PCP), coordinates her medical care, communicating and coordinating with the LBD specialist and other doctors. If your spouse has comorbidities (other medical conditions), the tests, treatments, and medications for those conditions could have a significant impact on how your spouse experiences LBD. You need a PCP who knows about LBD - or is willing to learn - and who will coordinate with specialists. Sometimes, a single doctor can provide both services, as with a geriatrician who serves as a PCP and also has special training and experience in dementia care, including LBD.

It is likely that your spouse already has a PCP. If you have not done so already, discuss the following with the PCP:

- Are you willing to communicate and coordinate with my spouse's LBD specialist and other specialists about tests, treatments, and medications?
- Will you be responsible for reviewing my spouse's medications on a regular basis and whenever new medications are prescribed to ensure that none poses significant risks or interacts adversely with other drugs?

From the Survey

In addition to an LBD specialist who is most often a type of neurologist, care partners take their spouses to a variety of other doctors.

	Percent
Primary care physician (PCP)	78.7%
Cardiologist	25.0%
Urologist	22.8%
Internal medicine specialist	8.1%
Pulmonologist	8.1%
Endocrinologist	6.6%
Gastroenterologist	6.6%
Geriatric psychiatrist	6.6%
Orthopedist	5.9%
Geriatrician	5.1%
General psychiatrist	4.4%
ENT (Ear, Nose, and Throat) Specialist	4.4%
Oncologist	3.7%
Neuropsychologist	2.2%
Internist	2.2%
Nephrologist	1.5%

Your Spouse's LBD Specialist

You may be looking for an LBD specialist for one of several reasons:

- Your spouse has symptoms that lead you to think that she has LBD or another neurological disorder, and you want a diagnosis.
- Your spouse has been tentatively diagnosed with LBD by a primary care physician. Now you need to find an LBD specialist to confirm the diagnosis and treat the symptoms.
- Your spouse has seen an LBD specialist, but you are not satisfied with the care and services offered, or you don't believe you can work with this doctor.

Regardless of the reason, follow the steps below to find the right match for you and your spouse.

Step 1 – Outline your basic requirements for an LBD specialist.

Some things are the same for everyone. You need a doctor who:

- has training and experience in diagnosing and treating LBD.
- is certified in his specialty (e.g., by the American Board of Psychiatry and Neurology - ABPN).
- is licensed in your state to practice the medical specialty.
- hasn't had malpractice claims or disciplinary actions.

Some things vary with the individuals involved. Do you need or want:

- a local doctor, or are you willing and able to travel? If so, how far?
- a doctor who accepts Medicare, Medicaid, and/or your private insurance plan?
- a doctor who is associated with a particular hospital or with a medical school? If so, which one(s)?
- a man or a woman doctor?
- a doctor who speaks the language you and your spouse speak at home, if English is not your first language?

Step 2 – Consider what type of specialist you think would be best for your spouse.

There are quite a few medical specialties that work with people who have dementia, including LBD. These are listed below. You can learn more about each at the links provided. Consider your spouse's primary symptoms as you review the focus of each specialty.

- Geriatrician http://www.americangeriatrics.org/advocacy_public_policy/gwps/gwps_faqs/id:3182
- General neurologist http://patients.aan.com/go/workingwithyourdoctor
- Geriatric neurologist http://www.ucns.org/go/subspecialty/geriatric
- Behavioral neurologist http://www.ucns.org/go/subspecialty/behavioral
- Memory disorder neurologist http://www.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/memory_disorders/conditions/
- Movement disorder neurologist http://www.mayo.edu/research/departments-divisions/department-neurology/programs/movement-disorders
- General psychiatrist http://finder.psychiatry.org/
- Geriatric psychiatrist http://www.aagponline.org/index.php?src=gendocs&ref=CareersGeriatricPsychiatry&category=Main

From the Survey

- Approximately three-fourths of the spouses were diagnosed with LBD by some type of neurologist:

General neurologist	38.2%
Geriatric neurologist	2.9%
Memory disorder neurologist	19.1%
Movement disorder neurologist	14.0%

- About half of the spouses are being treated by the doctor who diagnosed their LBD.
- These types of doctors are most frequently treating the spouses' LBD symptoms after diagnosis.

General neurologist	29.4%
Geriatric neurologist	1.5%
Memory disorder neurologist	19.9%
Movement disorder neurologist	14.7%
Geriatrician	7.4%
Primary care physician (PCP)	10.3%

Step 3 – Get referrals from people you trust.

Personal recommendations often result in finding a doctor relatively quickly. Consider these sources for suggestions on doctors to investigate further:

- Your spouse's PCP has a network of connections and probably knows your spouse and you well enough to make good recommendations.
- Family members and friends may have had positive experiences with the type of doctor your spouse needs. They may have heard from reliable sources about qualified dementia specialists.
- Your insurance company may maintain a list of trusted specialists.
- If you have joined a face-to-face or online LBD support group, members may be able to recommend specialists in your area.
- If a medical school near you has a department that focusses on dementia (perhaps a memory or movement disorder clinic), contact them for a referral. Often, they have multidisciplinary staffs who can address a variety of LBD symptoms.

Step 4 – Use online resources to locate potential specialists.

You can also check several or more online resources to find doctors to contact in person.

AAMC
Tomorrow's Doctors, Tomorrow's Cures
American Board of Medical Specialties
Higher standards. Better care.®

- U.S. News and World Report Doctor Finder – "U.S. News Doctor Finder is a free, searchable online directory of U.S. physicians that's designed to help consumers make informed decisions in their choice of doctors." You can search by specialty and location.
  See http://health.usnews.com/doctors
- "Find a Neurologist" at the American Academy of Neurology website – You can search by subspecialty and by city and state. There is not a separate listing for LBD or for memory disorders. Use the following to narrow your choices: Alzheimer's disease, behavioral neurology, dementia, movement disorders, and Parkinson's disease.
  See http://patients.aan.com/go/home
- AMA Doctor Finder – "This online physician locator helps you find a perfect match for your medical needs. Doctor Finder provides you with basic professional information on virtually every licensed physician in the United States. This includes more than 814,000 doctors."
  See https://apps.ama-assn.org/doctorfinder/
- Physician Directory at WebMD – You can search by specialty, condition, procedure, and location. See http://doctor.webmd.com/
- Physician Compare – "Physician Compare is a Centers for Medicare and Medicaid Services (CMS) website that helps you find and choose physicians and other healthcare professionals enrolled in Medicare…"
  See https://www.medicare.gov/physiciancompare/search.html

- Find a Psychiatrist from the American Psychological Association (APA) See http://finder.psychiatry.org/
- Find a Geriatric Psychiatrist - To locate a geriatric psychiatrist who is a member of the American Association for Geriatric Psychiatry. See http://gmhfonline.org/
- Lewy Body Dementia Scientific Advisory Council – Many of the physicians who serve on the LBDA Scientific Advisory Council see patients, or they might be able to refer you to a specialist.

See http://www.lbda.org/content/lbda-scientific-advisory-council-sac

- Alzheimer's Disease Research Centers - The National Institute on Aging funds 30 centers whose primary focus is on Alzheimer's disease. Many also conduct research on LBD and treat patients with LBD. See www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers
- Other online searchable directories obtain information from the doctors and ratings from their patients. You can search most of these by specialty and location.
    - Healthgrades.com
    - RateMDs.com
    - Vitals.com
    - Yelp.com
    - AngiesList.com

Step 5 – Select several doctors from your search who meet most, if not all, of your criteria.

From the various sources you have consulted, you should have obtained enough information to narrow your list to several candidates. Choose one doctor at a time to investigate until you find one who meets your criteria.

Step 6 – Contact the candidates until you find a match.

You can get some information by talking to a receptionist in the doctor's office, but you will need the doctor to answer other questions. Most doctors are open to an introductory phone call. Based on what you learn during the phone call, you can decide which doctor(s) to meet with in person. You will want to confirm the information you obtained from other sources, such as board certification, hospital affiliation, and insurance accepted. Some of the following questions may be more important to you than others:

- How many people with LBD has the doctor treated? How recently?
- Are the office hours convenient to your schedule and the times of day that are best for your spouse?
- How long does it usually take to get a routine appointment?
- How long does it take to get an emergency appointment?
- How much time does the doctor usually spend with a patient?
- What will be your primary method of communication between appointments if you have questions about your spouse's symptoms, treatment, or medications?
- What technologies does the doctor use and for what purposes:
    - E-mail
    - Text
    - Fax
    - Electronic health records (EHRs)/electronic medical records (EMRs)
    - Web portal such as My Chart that allows you to communicate with the doctor, access test results, manage your appointments, fill out pre-visit paperwork, request prescription refills, update medications and allergies, etc.

  - Some type of telecommunications application (e.g., Skype) to communicate with patients visually and verbally in real time via computer, tablet, or smartphone.
  - A computer physician order entry (CPOE) system. Instead of carbon copies, the doctor uses a desktop or laptop computer to order drugs and tests online. This can mean that prescriptions are easier to read and fewer errors are made. The doctor can send the prescription directly to the pharmacy so that it is ready to pick up when you get there.
  - A website or Facebook page
- Does the doctor have a nurse practitioner and/or physician assistant? If so, what are their responsibilities?
- Can laboratory work and other tests be done in the doctor's office or nearby?
- What are your impressions of the office staff from your observations and discussions with them?

In addition to getting answers to your questions, you will learn more by talking to the doctor on the phone and in person. Notice how she responds. Did the doctor:

- listen to you without interrupting?
- welcome your questions?
- fully answer your questions in a way that you understood?
- maintain eye contact when you spoke in person?
- take an interest in getting to know you and your spouse?
- have a personality and communication style compatible with you and your spouse?
- accept you as a key member of your spouse's healthcare team?
- respect your right to make decisions on behalf of your spouse?
- treat your spouse as a person and include her in the conversation?
- appear to be sensitive to any personal or cultural issues related to your race, ethnicity, religion, and/or gender?

Step 7 – Review your information, talk with your spouse, and make a decision.

Use the facts you've gathered along with your own and your spouse's opinions and feelings to select an LBD specialist. Choose the doctor you think is the best fit to treat your spouse's symptoms within a person-centered, relationship-based healthcare team.

Step 8 – Contact the specialist's office and start the process for your spouse to become a patient.

You will need to fill out paperwork, submit insurance forms, supply other information about your spouse, and make an appointment for your spouse's first visit. Hopefully, this will be the start of a positive shared experience. Remember, you are not obligated to continue with any doctor who is not meeting your spouse's needs.

5. Developing a Relationship with your Spouse’s LBD Specialist

What a relief it was to finally have a doctor who not only understood LBD, but also who was caring and compassionate! Dr. Parker took time getting to know Lilburn, the person, not just the patient. They bantered about common interests: basketball and jazz. He was concerned about my well-being, also. He was always available – by e-mail, personal phone number, and even texting. He always listened to both of us, and he respected the ideas I contributed to Lilburn’s treatment plan.

Ro and Lilburn.

You are probably reading this guide because your spouse

- has been diagnosed recently with LBD,
- has had LBD for some time or
- has a diagnosis pending based on symptoms common to LBD.

If your spouse already has an LBD specialist, do you want to improve your care-team relationship? Do you need to find an LBD specialist and start off with a good relationship?

First, what makes a relationship with a physician successful? Second, how does communication contribute to the relationship?

What are the Characteristics of a Successful Doctor–Patient–Care Partner Relationship?

Person-centered: The entire person, not just a patient with a set of symptoms, is the focus. You, the LBD specialist, and other members of the healthcare team base everything on your spouse as a person. He is a unique individual with his own interests, needs, abilities, feelings, and more. Each part of him as a person is considered. This includes much more than his activities, schedules, treatments, etc. All members of the care team support your spouse's efforts to maintain his personhood with dignity and respect throughout the journey, despite his having LBD. The team's goal is to do everything to preserve this personhood.

Engagement: Patients and their care partners are active, engaged participants. There are specific engagement behaviors that promote the best possible care for your spouse. These behaviors, as developed by the Center for Advancing Health, are shown in Table 1 in Section 1. Being engaged requires skills that you can learn over time as you work with various members of the healthcare team. At first, your spouse may be able to perform some of the tasks. Eventually, you will need to take almost 100% responsibility for the engagement behaviors.

Shared decision-making: The doctor does not make all decisions about treatment. You, your spouse, and the doctor come to a mutual agreement. You base this agreement on:

- the doctor's expert guidance
- the knowledge you have acquired
- factors such as your spouse's and your preferences, values, and risk tolerance
- decisions outlined in your spouse's advance directive

Mutual respect: You respect the LBD specialist as a person, and the physician, in turn, respects you and your spouse as individuals. Each of you respects what the others have to contribute to your spouse's healthcare. The LBD specialist brings expertise and experience. You and your spouse bring your knowledge of your spouse's symptoms, reactions to treatments and medications, and your family's preferences and values.

Mutual honesty: It is important for you and your spouse to be candid with the doctor. You share all symptoms, even those that might be embarrassing. The doctor needs to know the truth about your spouse's compliance with the treatment plan and medications. You let the LBD specialist and others know that you expect them to be honest with you. You want to know the truth about all aspects of the diagnosis, prognosis, risks, and elements of the treatment plan.

Empathy: You feel a compassionate connection between the LBD specialist, you, and your spouse. The doctor sees things from your perspective, communicates his or her understanding, and acknowledges your spouse's and your emotions. Empathy is a two-way process. You understand that the doctor is a person, too, with many competing demands for her time, energy, and skills.

Effective communication: Communicating in a way that fosters good engagement requires a variety of elements, including:

- active listening
- understanding one another
- not being afraid to ask questions
- being aware of nonverbal communication
- mutual discussion (rather than one-way lectures)
- communicating in a way that your spouse can understand as his cognitive skills decline.

Cultural competence. The doctor is sensitive to your spouse's and your cultural, philosophical, religious, and social preferences. These may be related to your race, ethnicity, nationality, religion, or another factor. The doctor communicates, uses treatments and interventions, and approaches all aspects of your spouse's care with an understanding of and appreciation for your culture and belief systems.

From the Survey

Most care partners of spouses with LBD are satisfied with their relationship with their LBD specialist.

Which of the following is true of your relationship with your spouse’s DLB doctor? (Check all that apply.)

	Percent
You and your spouse feel a personal connection with the doctor.	54.5%
You and your spouse’s DLB doctor listen to one another and you feel heard.	79.2%
You are comfortable asking questions.	95.0%
You are a collaborative participant in your spouse’s care.	85.1%
You have mutual respect.	78.2%
You have mutual honesty.	74.3%
You have mutual discussions, not one-way communication.	79.2%
There is shared decision-making.	71.3%

What are the Purposes of Communication with Your Spouse’s LBD Specialist?

Effective communication is the cornerstone of a successful relationship with your spouse’s LBD specialist and other members of his healthcare team. Communication is important not just during office visits. You need good communication between visits, during emergencies, and during hospitalizations. Your relationship with the LBD specialist is likely to span 5 –7 years or longer. It is best to get off to a good start and continue for the duration. If your communication with the LBD specialist is not effective, you can take actions to improve it.

You, your spouse, and the LBD specialist have a variety of reasons to communicate. You all share some reasons. Each of you also has your own reasons to communicate. You need to communicate between visits, during office visits, and during trips to the ER and hospitalizations. Related sections of this guide address the specific goals for each of these situations.

The general purposes of communication from your perspective as care partner include the following:

- establishing and maintaining rapport with the LBD specialist throughout your relationship
- providing information about your spouse
- obtaining and fully understanding medical information
- expressing emotions and having them addressed
- engaging your spouse to the extent possible
- preserving your spouse's personhood

What are the Barriers to Effective Communication?

Most doctors, patients, and care partners want to communicate well with one another. Even so, communication too often breaks down or does not get off to a good start. Your awareness of why this happens can help you take actions to avoid or overcome such problems.

<u>Is there too little time?</u> The average amount of time that a doctor spends with a patient during each office visit in the United States is between 10 and 17 minutes. Physicians work under financial pressures from insurance companies, Medicare, and Medicaid. They need to see more patients because they are paid by the visit based on the reason(s) for the visit and procedures they perform. They are not paid by the time spent. There are formulas for the amount to be paid built into the coding systems used throughout the U.S. for billing. Medicare uses the ICD10 (International Classification of Diseases, 10th Revision). Non-Medicare visits use CPT (Current Procedural Terminology) codes from the AMA (American Medical Association).

Efforts are underway to allow doctors to spend more time with patients. For now, however, you, your spouse, and the LBD specialist have to make the best use of limited time. There are strategies that promote the quality of time rather than being limited by the quantity of time. Some of these are discussed in Sections 6, 7, and 8 of this guide.

<u>Do you feel intimidated or uncomfortable talking with the doctor?</u> Your beliefs, attitudes, and expectations can interfere with effective communication. For example, determine if any of these apply to you and/or your spouse:

- You view the doctor as such an expert that you think you won't be able to communicate on that level. You don't want to appear unintelligent.
- You have had bad experiences in the past with doctors. The doctors may have been very authoritarian, paternalistic, brusque, or unconcerned about you and your spouse as individuals.
- You are afraid of the answers you might get, so you avoid asking questions.
- You think that the doctor's time is too valuable for issues that may not be very important.
- You believe that little – or nothing – can be done for your spouse. You doubt that communication will do any good.

How does your role as a care partner to a spouse with LBD interfere with effective communication?

Most of what is written about person-centered, relationship-based healthcare is about patients and doctors. You are in an LBD-specific situation. Your spouse is gradually losing his ability to convey symptoms and emotions, understand options and treatments, and interact verbally and nonverbally. You will evolve into the primary person who interacts with his LBD specialist. Perhaps, you have already done so. However, you and the LBD specialist need to know when, how much, and in what ways to keep your spouse engaged in the communication to his best ability. This changes over time. It also changes daily and hourly with the many cognitive and emotional fluctuations symptomatic of LBD.

What are the Characteristics of Effective Communication?

When you, your spouse, the LBD specialist, and other members of the healthcare team communicate effectively,

- you are more likely to be satisfied with your spouse’s care
- the allotted time can be used more effectively
- your spouse, with your support, is more likely to follow the specialist’s instructions
- your spouse is more likely to have better health outcomes

The type of communication that promotes these results has the characteristics discussed below.

Mindful. You may be familiar with the concept of mindfulness that has become quite popular. “Mindfulness means paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally.”

In mindful communication:

- Each person pays attention to what is happening at the time.
- There is dynamic sharing of information and emotions.
- Negative emotions (anger, fear, guilt, etc.) are accepted but controlled.
- The tone is positive.
- Participants attend to, respond to, and perceive information in an alert and active manner.

Two-way. Communication is a dialog, not a monolog or lecture. There is give-and-take, sharing, and reciprocity.

Goal-oriented. Participants each have goals that they want to achieve. Often these must be ranked by priority because not all can be accomplished in the time available.

Person-centered and relationship-based. Each opportunity for communication reinforces the characteristics of a successful doctor-patient-care partner relationship:

- person-centered
- engaged
- shared decision-making
- mutual respect
- mutual honesty
- trust
- empathy
- cultural competence

What Actions can You Take?

Effective communication doesn't just happen. It requires conscious effort and specific actions to achieve the type of communication that fosters person-centered, relationship-based healthcare for your spouse.

- Be prepared. Have information and questions ready. Bring notes and have your LBD portfolio with you!
- Let the doctor know what your goals are.
- Recognize and work toward your spouse's goals as well as the doctor's goals.
- Be aware of the present moment.
- Focus on specifics. Talk about what actually happened, rather than making general statements.
- Be a good listener. "We have two ears and one mouth so that we can listen twice as much as we speak" (Epictetus).
- Ask questions if you don't understand the doctor's explanations or instructions.
- Paraphrase – repeat back in your own words – what the doctor says to be sure that you understand.
- Speak frankly, openly, and honestly.

- Be concise – get to the point – to make the best use of time.
- Bring up problems, issues, concerns, etc. without waiting for the doctor to ask.
- Be willing to discuss topics you find uncomfortable.
- Be aware that your nonverbal behavior— facial expressions, body language, eye contact, etc.—also communicates.
- Be aware of your emotions, express them, but don't let them control the communication.
- Monitor your tone of voice.
- Maintain eye contact.
- Be assertive. Don't be afraid to speak.
- Be persistent.
- Be polite, gracious, and diplomatic.
- Be understanding and appreciative.
- Ask the doctor to listen to your complete question or answer if she interrupts. "Studies have shown that patients are permitted 12 to 18 seconds of talk time before they are redirected (or interrupted) by their doctor."
- Ask questions and voice concerns to the appropriate person. The doctor may not be the best person. Asking her wastes time she could devote to more important issues with you.
- Include your spouse to the extent his ability allows.

What Methods Can you Use to Communicate with Your Spouse's LBD specialist?

Not all communication between you and the LBD specialist takes place face-to-face. Between office visits and in emergencies, there are several ways that you can communicate with the LBD specialist.

By telephone. There are times when you need to communicate directly with the LBD specialist between office visits. Find out how you can do so before the need arises. Some doctors require you to go through their office phone number with a receptionist or nurse before talking to you directly. Increasingly, doctors are giving their patients their private home or cell phone numbers so that they can be contacted directly. If the LBD specialist gives you her private home and/or cell phone number, discuss with the doctor under what conditions you should and may use that number. Doctors don't have a way to bill for phone calls, and they face some legal and financial risks. Follow these guidelines when calling the LBD specialist.

- Know where to call when. Doctors often work from more than one office. Have their office hours, locations, and phone numbers handy and in your spouse's LBD portfolio.
- Know what number you should call after hours.
- Call only under the conditions you have discussed with the doctor.
- Have a specific question or concern ready to present concisely. Write it down; if you are in crisis you may forget what to say.
- Let the doctor know what you expect as a result of the call.
- Don't expect to solve significant problems via a phone call. Discuss the appropriate follow-up.

E-mail. Sending an e-mail message allows you to compose your questions or provide information to the doctor with care. E-mail allows the doctor to read and reply when she has the time. As with phone calls, some doctors have messages sent to their nurse or receptionist who either responds or forwards the message to the doctor. Other doctors communicate directly with their patients via their e-mail account. Ask the LBD specialist about her policy on e-mail communication and follow that policy.

Negotiate with the LBD specialist to expect e-mail updates from you on the status of your spouse's symptoms before each office visit. The doctor will be better prepared for the visit. Also, you can communicate information via e-mail that you might not want to share in front of your spouse.

The American Medical Association (AMA) has guidelines for patient-physician electronic mail. From your perspective as the care partner, here is what you should do.

- Ask the doctor for the turnaround time for messages.
- Don't use e-mail when you have an urgent matter.
- Be sure you understand privacy issues.
- Ask who besides the doctor takes care of e-mail when he is away.
- Be aware that the doctor keeps electronic and/or paper copies of e-mail communications.
- Ask the doctor about how she uses e-mail; e.g., for you to ask questions, provide information, request prescription refills, schedule appointments, etc.
- Ask the doctor whether any subjects should not be discussed via e-mail.
- Include the purpose of the e-mail in the subject line of the message; e.g., prescription, appointment, symptom report, medical advice, billing question, etc.
- Put your spouse's name and patient identification number in the body of the message.
- Make your e-mail message short and to the point.
- When you get a reply, let the doctor know that you have received it and that you are following through on any instructions.

Use other forms of communication for emergencies. You don't know how long it will be before someone reads your e-mail. Use the telephone or texting if the LBD specialist accepts text messages (see below).

Patient portals. Many physician practices, medical centers, and hospitals have patient portals such as MyChart. A patient portal gives you 24-hour access to your spouse's health information via a secure online website. Patient portals provide another avenue for communication with the LBD specialist and your spouse's other doctors.

If you have access to a patient portal, you can likely

- view information about
    - recent doctor visits
    - discharge summaries
    - medications
    - immunizations
    - allergies
    - lab results
    - and more
- exchange e-mails with your spouse's doctors
- request prescription refills
- schedule non-urgent appointments
- check benefits and coverage
- update contact information
- make payments
- download and complete forms
- view educational materials

NOTE: It is important that you do not use a patient portal for urgent medical matters. Call the LBD specialist or 9-1-1 for urgent or emergency concerns.

Texting. Texting could be a fast, direct, and simple way to communicate with doctors. It is not widely used because of security and HIPAA issues. SMS text messages can be read by and forwarded to anyone. They are unencrypted (not coded or scrambled), and stay on phones forever. Thus, personal health information is not protected as required by regulation.

The Joint Commission (a nonprofit, standards-setting medical accreditation and certification program) has banned doctors from using text messaging to communicate personal health information. If a doctor violates this ban, she can be fined $50,000 for the first violation.

Texts can be exchanged if they do not include personal health information. Hopefully, soon there will be applications that allow doctors to communicate via texting in a way that complies with security and HIPAA requirements. One such mobile-to-mobile texting application is available now. Spōk Mobile Spheres encrypts messages to protect sensitive information. See http://info.spok.com/spheres.

Faxing. There may be times when you need to send information to or receive information from the LBD specialist. If you have something in paper form, such as a laboratory report, it may be most convenient and fastest to send it via facsimile. The security rule that applies to texting and e-mail does not apply to faxes because the personal health information was not electronic before its transmission.

When you fax, include a cover sheet with your spouse's name and an indication of the subject matter. If the fax contains personal health information, include a statement of confidentiality on the cover sheet. Do not put personal health information on the cover sheet.

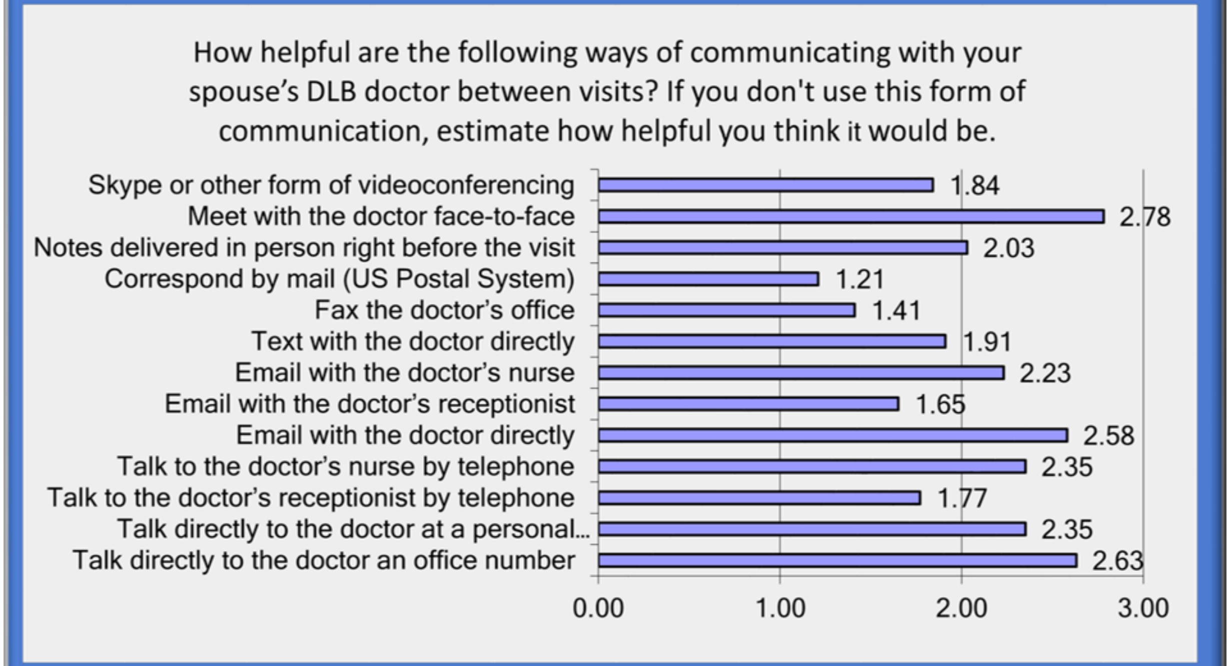
Correspondence via the U. S. Postal System. If you don't have access to a fax machine and cannot send something via e-mail, you can send it by US mail. You might need to mail copies of forms, reports, or other documents to your spouse's doctor. You may want to send an update on his symptoms and issues that you'd like to discuss before each appointment with the doctor. Do indicate on the envelope that the correspondence is confidential.

Notes delivered in person. It is a good idea - even if you have sent something via another communication method - to take copies to the office visit. The doctor may not have had a chance to read the documents, or they may have been filed. The copy can refresh her memory and be used during the visit. As described in Section 6 of this guide on office visits, having a brief statement of your goals for the visit and a short summary of your spouse's current symptoms can focus the visit.

From the Survey

- Care partners communicate with their spouse’s LBD specialist almost exclusively by telephone at the doctor’s office number.
- Very few care partners use other modes of communicating directly with their spouse’s LBD specialist between visits:

Never at a personal number	77%
Never via email	58%
Never via text	91%
Never deliver notes in person	72%
Never meet face-to-face	76%



- Care partners would like to communicate in ways that they don’t now use.


culture
engagement
person centered
honesty
relationship
communication
empathy
Shared decision-making
mutual respect

6. Before, During, and After Visits to the LBD Specialist

My husband, Glynne, was diagnosed with Lewy body dementia at the age of 57. We had waited four months for an appointment to see the LBD specialist in the area. I had a general idea where the building was, but I didn't go by beforehand or MapQuest it. Needless to say, I drove in circles for ten minutes before our appointment. I started to get frustrated, Glynne started to get frustrated, and it all grew worse from there. We got to the appointment just in time, only to wait two hours for the doctor. By the time we met the doctor, we were exhausted and frazzled – as you guessed, it didn't go well. That is when I learned to be prepared. Over the last 16 months, I learned to ask questions, do my research, and be prepared.

Randi and Glynne

Your spouse needs to visit the LBD specialist on a regular basis and also when a concern requires the doctor's attention between scheduled visits. She may also need to see her primary care physician (PCP) for any conditions that the LBD specialist does not treat. The LBD doctor assesses the symptoms and progression of the disease, positive and negative reactions to medications, and effectiveness of the treatment plan. As an engaged care partner, you have tasks before, during, and after your spouse's doctor's visits.

Before Visits to the LBD Specialist

Before you make an appointment. Be ready with all of the information you need to make an appointment.

Add the relevant information about the doctor's practice to the LBD portfolio.

- The doctor's full name and specialty
- Complete contact information

  - Office phone number
  - Other phone numbers
  - Office fax number
  - E-mail address
  - Web URL
  - Full address including suite or room number
- The days and hours that the LBD specialist sees patients
- How to make an appointment: hours and number to call, other ways to make appointments (e-mail, Internet patient portal, etc.)
- The names and job titles of office staff you talk with by phone and see during visits

Have your LBD portfolio available for needed information and forms, especially for the first visit. You will likely need:

- Your spouse's name, address, date of birth, telephone number, social security number, and emergency contact information.
- Information and documentation of her insurance coverage
- Names and contact information for her other physicians
- Copies of medical records
- Medical and surgical history
- Family health history
- Copies of living will/advance directive, medical power of attorney (MPOA), and Do Not Resuscitate order (DNR) if applicable.
- Medication record that includes all prescribed drugs, supplements, and over-the-counter (OTC) drugs with the information outlined in Section 3 (Creating an LBD Portfolio)
- Food or drug allergies
- The symptom observation log with up-to-date information.

Making the appointment. It is best to make the first appointment by phone so that you can ask and answer questions. After that, you can schedule appointments by phone, e-mail, or the web-based patient portal. The following are topics to discuss with the receptionist. After a visit or two, you will know the answers to some of these questions.

Let the staff know about:

- The time of day to see the doctor that is best for your spouse when she is usually alert, rested, calm, and not hungry.
- Any arrangements your spouse and you require, such as assistance getting her from the car to the office or having a wheelchair available.
- Information about insurance coverage.
- Your medical power of attorney (MPOA), complete contact information, and role during the visit (e.g., staying with her throughout the visit and answering questions about symptoms and medical history that she is not able to answer).
- Requesting time to talk with the doctor about sensitive issues when your spouse is not present.

Ask about:

- The time of day when there is usually the shortest wait (e.g., first appointment in the morning or after lunch) and estimated waiting time.
- How soon the doctor can see your spouse. If the wait is longer than desired, ask to be called if someone cancels an appointment.
- Information about parking and getting to the office (e.g., handicapped parking, cost to park, distance to walk, elevators, etc.).
- Required forms and paperwork: Can they be completed beforehand? If so, by mail, online, or fax?
- Medical records needed by the doctor: Have they been transferred? If not, plan for the transfer.
- The appointment cancellation and no-show policies
- How to provide information to the doctor before the appointment: What is the doctor’s preference for how to receive this?
- Requirements for any exams or tests the day of the appointment (e.g.,
- Can she eat before the visit?)
- Confirming the date and time; record it in your paper or electronic calendar.
- Whether you can expect a reminder call before the appointment date.

<u>Prior to the appointment</u>. Between making the appointment and seeing the doctor, do the following to make the visit go as smoothly as possible.

- Confirm that the doctor's office has received all of the required paperwork. If not, follow up.
- If you are not familiar with the location of the office, put the address in your GPS or print a map with driving directions; make a test drive.
- Ask a family member or close friend to accompany you - someone you trust to take good notes. This allows you to concentrate on your spouse and the doctor. The person can also help you get your spouse in and out of the car, and between the parking lot and office. If you have an aide who assists with your spouse's care at home, he or she might be a good person to go with you.

- Tell your spouse about the appointment in a positive manner and answer her questions about the visit.
- Set the goals you want to accomplish during the visit. . Print or type this information on a card to give to the doctor:
  - Summarize several issues that are most important for the doctor, you, and your spouse to address during the visit.
  - Include issues that your spouse has raised.
  - Be as concise as possible in stating the symptoms and key points (onset, changes, frequency, timing, etc.).
- Prepare the questions that you want to discuss with the doctor without your spouse being present.
- Provide written information about your spouse in the form accepted by the doctor (e.g., e-mail, Internet patient portal, US mail). This saves time during the visit and allows you to tell the doctor about things you don't want to discuss in front of your spouse. Make a copy to bring to the visit.
- Review your spouse's medications to identify any that need prescription refills or any that you want to talk to the doctor about changing.

The day of the office visit

Before you leave the house. Allow plenty of time before the scheduled appointment time to do the following without rushing your spouse.

- Pack a bag that includes
    - a sweater
    - a small snack
    - a water bottle
    - something to occupy her mind and hands during the wait (perhaps a mobile device)
    - incontinence supplies if needed
    - wipes
    - a change of clothes if she is likely to soil her clothes
    - the LBD portfolio
    - copies of information you sent to the doctor
    - your goals and questions for the visit.
- Wake her early enough to have her ready to leave on time.
- Remind her of the doctor's appointment and tell her what to expect.
- Have her complete her hygiene activities (shower, brush teeth, comb hair, etc.) with as much assistance as she needs from you or an aide.
- Serve her breakfast or lunch depending on the time of the appointment unless she is going to have tests that require fasting.
- Have her go to the bathroom shortly before leaving the house.
- Settle her into the car without rushing. If a friend or family member is driving, sit in the back seat with your spouse. If you are driving and a friend is going with you, it may be best if your spouse and friend sit in the back seat. If it is just the two of you, have your spouse sit in the front passenger seat. You want her to get the attention she needs during the drive.
- If you have a handicapped placard, be sure to take it with you.
- Leave in enough time to get to the office 15 minutes before the appointment. Allow time for traffic, parking, and getting your spouse out of the car and into the office.

Getting to the office. Your spouse may be comfortable and calm riding in a car, but some people with LBD become agitated. To keep her calm, stay calm yourself even if there is traffic and aggressive drivers. Play soothing music that she enjoys. Give her something to hold – a stuffed animal, squeegee ball, or religious article. Talk about topics that are pleasant for her. Use your GPS or printed driving directions to navigate to the office if you are unfamiliar with the route. Park in the most convenient spot to access the office, using a handicapped space if you have a handicapped placard. If you have arranged for assistance in getting her between the car and the office, call to let the office staff know where you are parked. Even if she doesn't usually use a wheelchair, use one if it is a long walk to the office and she has any gait, balance, or endurance problems.

Checking in and getting started. Let the receptionist know when you arrive. Sign in and take a seat if there are other patients ahead of you. When it is your turn, the receptionist will ask for your spouse's identification and insurance cards. If you have completed forms and paperwork ahead of time, you may or may not have additional paperwork.

It is likely that you will have to wait for the next step. Your spouse may feel uncomfortable in new surroundings with different faces and voices. This may cause some agitation. If it appears that it will be a while before you go to the exam room, keep your spouse calm and comfortable. Ask if she is cold and needs a sweater or if she is thirsty.

Before your spouse sees the doctor, a nurse or technician will take her vitals (blood pressure, temperature, pulse, and breathing rate). The nurse may weigh your spouse or ask for her most recent weight and height. If she has other conditions, the nurse may do other tests, such as an A1c test for diabetes or an INR test if she takes a blood thinner.

He or she will also ask questions about your spouse's medications and allergies. In most practices, the information is entered into the electronic medical record (EMR) system. Give the nurse a copy of the medication record from the LBD portfolio to use in entering the data,

and ask for this to be included in your spouse's paper file. Let the nurse know if your spouse needs any medications refilled. The nurse will ask you for the purpose of the visit. Give him or her the card with your goals for the visit and questions for the doctor. Sometimes this preliminary work is done in the exam room where your spouse and you will see the doctor. Other times, another room is used for this purpose.

Seeing the doctor. You spend a lot of time and energy to prepare for visits with the doctor. These efforts pay off because the doctor does not have a lot of time to spend with you and your spouse. Overall, a 13 – 16 minute visit is most common, although neurologists spend more time with each patient: a median of 25 minutes. As shown below, more than half of care partners who responded to the survey indicated that the LBD specialist spent 30 minutes or less with their spouse. Already having a lot of information about your spouse, your goals, and your questions allows the doctor to focus on your spouse and you during this limited time.

From the Survey

Typically, how long does your spouse's LBD doctor spend with your spouse and you during each visit?

	Percent
15 minutes or less	19.2%
16 - 30 minutes	34.6%
31 - 45 minutes	22.1%
46 – 60 minutes	19.2%
More than 60 minutes	4.8%

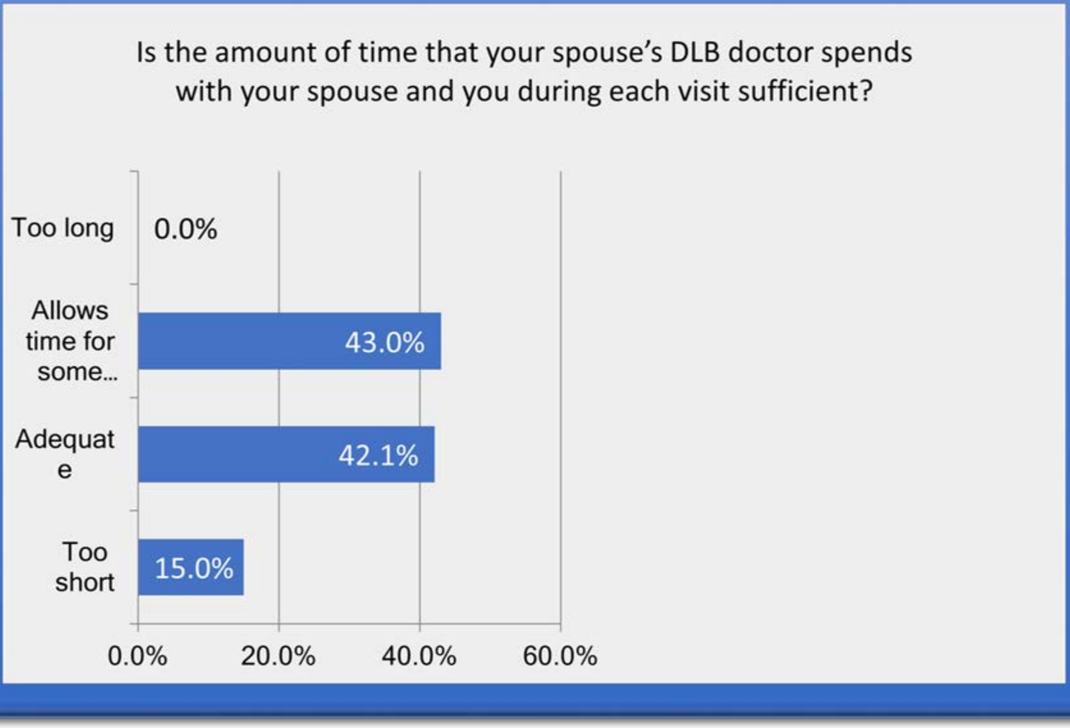
<u>The interview</u>. Usually, the doctor begins by interviewing your spouse and you. Let the doctor take the lead in asking questions. Do go over your spouse's and your goals for the session early in the interview. Allow your spouse to answer as many questions as she can, and indicate to the doctor that you want her to be engaged in the session. However, when your spouse is unable to answer a

question completely or accurately, provide the additional or correct information. Refer to items in the LBD portfolio as needed to provide requested information.

Either you or the person who has accompanied you begins note-taking at the start of the interview and continues for the duration of the session. Another possibility is to record the session if the doctor agrees to it. If the doctor asks a question or says something that you don't understand, ask for clarification.

In the first few sessions with the doctor, he gets acquainted with your spouse and learns more about her medical, family, and social history asking for details that will help him understand your spouse's current condition better (.e.g., reactions to surgeries, anesthesia, medications; onset and changes of symptoms).

From the Survey



The exam. The doctor examines your spouse depending on your spouse's current symptoms and how well the doctor already knows her. The doctor may conduct cognitive and psychological tests as well as a physical exam. Your role is to provide reassurance if your spouse becomes apprehensive and to follow the doctor’s lead in providing information during the exam. Mostly, you are an observer whose presence comforts your spouse. If another person has accompanied you, he or she might leave the room during the exam. In this case, you take notes during the exam.

The treatment plan. After reviewing and discussing information about your spouse and then examining her, the doctor discusses the treatment plan and next steps. For example, the doctor might recommend a change in one or more of your spouse’s medications, increasing or decreasing the dosage, changing when or how it is taken, or discontinuing it. Write down the specific instructions on how to implement these changes and say the directions in your own words to be sure that you understand them. Ask the doctor to clarify anything that is not entirely clear. Your spouse might get a new prescription. Ask questions such as the following:

- What are the reasons for the change in medications?
- Why are you prescribing the new drug? What is the purpose of the medication?
- Are there other drugs to treat this symptom/condition? If so, why are you prescribing this drug instead of one of the others?
- If a generic is available, why have you prescribed the brand name? Is the generic as effective as the brand name?
- What results should I look for in my spouse with this drug?
- How long will it take to observe the effects of the medication?
- How long will it take to know if the medication is not working for my spouse?
- Have you prescribed this drug for other patients with Lewy body dementia? If so, how effective has it been?
- What are the primary negative short-term and long-term side effects of this medication – especially for someone with LBD? What should I look for in my spouse?
- Are there ways to minimize the negative short- or long-term side effects?
- If my spouse shows negative side effects, what should I do?

Now is the time to ask the doctor to write renewals for existing prescriptions. Some doctors still do this by hand, but many give a computer-generated script or send one electronically to a pharmacy or mail-order provider.

The doctor might order lab work or other testing; some might be done in the same facility immediately while others require travel to another location, perhaps a hospital.

- Ask the purpose of the tests and get information about how to schedule and prepare your spouse for the exam (e.g., must she fast, can she take all of her medications, etc.).
- If the testing is invasive or has risks, discuss the risks and if the benefits outweigh them.
- If an anesthesia or sedative is required for the test, discuss the risks of these drugs for people with LBD. Request alternate medications. Refer to the references in the LBD portfolio on medications that should be avoided or used with caution (Section 3 of this guide).
- Some tests, such as neuroimaging (e.g., MRI) may cause your spouse emotional and physical stress. Discuss what can be done to avoid that.
- Finally, ask how the results of these tests might affect your spouse's diagnosis and treatment plan.
- Ask for a copy of the results to be sent to you or posted to your spouse's patient portal account. Find out how long it will take to get the test results.

The doctor might also do one of the following:

- Order physical therapy in the community.
- Order home health care (visiting nurse, aide, physical therapist, occupational therapist, and/or speech therapist).
- Order durable medical equipment (DME) such as a wheelchair, bedside commode, Hoyer lift, or hospital bed.
- Refer your spouse to another specialist for a condition he doesn't treat.
- Ask you to schedule an appointment with your spouse's primary care physician.

- Recommend surgery. This requires quite a bit of discussion and possibly time for you to research the procedure, consider the pros and cons, and perhaps seek a second opinion.

Before the session ends, be sure that you are clear on everything the doctor says and know what the next steps are. Ask the doctor for printed handouts or links to Internet resources on symptoms, medications, and treatments you want to learn more about.

The doctor will let you know when he wants to see your spouse again. He may schedule it in his computer-based system, or you can make arrangements with the office scheduler. Either way, make sure you receive an appointment card. Put the date and time in your print and/or electronic calendar right away.

From the Survey

Typically, how often does your spouse see the DLB doctor?	Percent
Once a month or more often	7.3%
Once every two months (about six times a year)	10.1%
Once every three months (about four times a year)	17.4%
Once every four months (about three times a year)	21.1%
Once every six months (about twice a year)	31.2%
Once a year	4.6%
Other (please specify)	8.3%

Most care partners think that their spouses see the DLB doctor at the right frequency.

	Percent
Not often enough	19.3%
Often enough	80.7%
Too often	0.0%

After the Office Visit

You may receive a printed summary of the office visit. Review this before you leave the office to verify the information is correct and that you understand the follow-up instructions.

When you get home, go over the notes from the visit and the summary you received from the doctor. If anything is not clear, call the office for clarification.

Fill new prescriptions promptly. Follow the instructions for the new medications and/or changes to medications carefully. Monitor your spouse for positive and negative reactions and record them to share with the doctor. Call the doctor if your spouse has adverse reactions to any of her medications.

Follow up on other instructions, such as:

- Schedule the tests the doctor ordered.
- Schedule appointments with other doctors who the LBD specialist wants your spouse to see.
- Help your spouse with any lifestyle changes (e.g., diet and nutrition, exercise, sleep).
- Coordinate with a home health agency if the doctor ordered those services.
- Arrange for the delivery of durable medical equipment if the doctor ordered any DME. When it is delivered, ask for instructions on how to use the item(s).

Discuss the office visit with your spouse. Ask about her feelings and opinions. Use a positive tone to provide the groundwork for introducing new aspects of her care plan.

- What did you think of the doctor? Do you like him?
- Do you think that the doctor listened to both of us?
- Did you understand what the doctor said?
- Did we have enough time to ask the doctor questions?
- How do you feel about what the doctor wants you to do?

Also, review in your mind what you thought of the session and the doctor. Are you satisfied with how the doctor communicates and the type of relationship you have? Do the communication and relationship match the characteristics and guidelines discussed in Section 5? If not, what actions can you take to improve the communication and relationship?

Don’t hesitate to call the doctor if

- your spouse’s symptoms get worse
- it appears that she is having negative reactions to a medication
- your spouse is unable to or won’t take a prescribed medication
- you have not received the report on any testing
- you don’t understand the test results you have received


office visits
vitals
exam
don't rush spouse
treatment plan
ask questions
interview
LBD portfolio
appointment
set goals
follow-up
paperwork
best time
note-taker
medication review

7. Before, During, and After Trips to the Emergency Room

The first time I took Burk to the ER with kidney pain, I questioned everything they did for him. The ER doctor was a very matter-of-fact person and, at one point, I thought that she resented my endless questioning of every little detail. I pulled her aside and said, "I am not trying to question your judgment. I respect the fact that you are the physician.” She stopped me before I could continue to apologize, looked me dead in the eye and said, "Never stop asking questions. Not everyone is well versed in LBD. I just finished a rotation in neurology under the LBD specialist who diagnosed your husband, so I am very up on LBD treatment. You are your husband's advocate and his only real voice in the ER. Never, ever stop. It's better to annoy a doctor than risk devastating, life altering treatment.” She started to walk away then turned around and said "Promise me that you will fight like a dog. It's your most important job."

Jane and Burk

You never know when your spouse will have a medical emergency. It might be one related to a symptom of Lewy body dementia (LBD) or another of his conditions. A urinary tract infection (UTI), dehydration, a fall, trouble breathing, significant pain, or other serious symptom often requires emergency care. As noted by the Lewy Body Dementia Association (LBDA), it is important to be prepared. More than half of LBD families had an emergency during the prior year. A majority (64 percent) of respondents to an LBD caregiver survey indicated that their loved one had had a crisis within the past year, and they most frequently sought help at a hospital emergency room (ER). (Although ER is still used, most units are now called emergency departments.)

From the Survey

- 58% of the spouses with LBD had been to an ER.
- 45% of care partners had called 9-1-1 before going to the ER.
- 48% were transported by ambulance; 48% were transported by private vehicle; 4% were transported by police.

When faced with your spouse's medical emergency, you need to act quickly and appropriately; therefore, it is important to be prepared before a crisis occurs.

How to Select an Emergency Room

Since your spouse will likely need an ER at some point, find the best one while you have the time and can make an informed, unpressured decision.

If you call 9-1-1 and an ambulance transports your spouse to an emergency room, you may give up control of where your spouse will go. The emergency team may be required to take him to the hospital they determine would provide the best treatment – often the closest one. If time is a critical factor, the ambulance emergency team can start treatment on the way to the ER. However, about 80% of ER patients do not arrive by ambulance, so if you decide it is safe to use a private vehicle, you may go to the closest ER or your preferred ER.

One of your spouse's doctors, perhaps the LBD specialist, may be affiliated with a hospital. This is more likely if a doctor is associated with a university medical school and hospital. If this is the case, it would be best to go to the ER at the hospital where your spouse would be treated by a doctor who knows him. This would facilitate a transition from the ER to the hospital should that be needed – and it often is. However, many doctors are not affiliated with a hospital, and patients are treated by *hospitalists* who are specially trained in the care of hospitalized patients. They are often board-certified internists.

If your spouse has been hospitalized recently and you were satisfied with his care, consider going to the ER associated with that hospital. It already has his records and it is more likely that preexisting conditions and prior health history will be in their record system. The same hospitalist might see your spouse if he is admitted to the hospital from the ER.

If you are choosing a new ER, get opinions from people you trust: your spouse's LBD specialist and other physicians, an emergency medical technician (EMT), a police officer, and friends who have been to ERs in your area. Ask them where they would go or where they would take a loved one.

There may be several emergency rooms close enough for you to consider, or there may be only one. Learn more about the ERs by scheduling a visit, asking questions, and observing the environment. You will want to know the following:

- Is there someone on the ER staff who has specialized training and/or experience in the care of older adults with dementia, in particular LBD?
- Is there up-to-date medical technology?
- What types of credentials do staff members hold? For example, are there board-certified ER physicians?
- Do the ER and hospital use medication reconciliation and full pharmacy reviews to reduce the chance that your spouse will get incorrect medications or medicines at the wrong doses?
- Do they do anything to reduce the stress of an ER visit for someone with dementia? People with dementia may experience psychological and behavioral symptoms in the often-chaotic ER environment. Can they move the person to a quieter, calmer room if there is a long wait?
- Would the environment be comfortable for your spouse: Are there hand rails, non-glare lighting, reclining exam chairs, warming blankets, bedside commodes, and other things to meet the needs of a person with dementia?
- How does the medical staff treat their patients? For example, do they treat them with respect and offer comforting words?
- Does the ER accept your medical insurance plan?

When you have decided upon an ER, include information about it in the LBD portfolio and on your 9-1-1 emergency card (see below). Be prepared to drive to the ER in an emergency. Map the route, put the address in your GPS or print out a map with directions, and do one or more test drives to the ER.

What to Have At the Ready

Families are told to have a bag of items ready to take to the hospital before the birth of a baby. In the same way, you should have things at the ready in case your spouse requires a trip to the ER. Have the following ready to go:

1. Your spouse’s LBD portfolio - See the Section 3 for what should go into this portfolio.
2. A grab-and-go bag of items for you and your spouse
    a. Items to occupy your time while waiting: something to read, music with headphones, favorite games, something for your spouse to hold on to (stuffed animal, squeegee ball, etc.). What is used will depend on his condition.
    b. A jacket or blanket for each of you to keep warm; ERs tend to be cold.
    c. A change of clothes for you and your spouse
    d. Toiletry items: toothbrushes and toothpaste, wet wipes, lotion, hand sanitizer, tissues, etc.
    e. Disposable, absorbent underwear if your spouse is incontinent
    f. Items used to calm your spouse, such as essential oils, family photos, etc.
    g. Light, nonperishable snacks to be consumed by your spouse only if approved by the ER staff
    h. Money for vending machines
    i. Phone and charger
    j. Medical face masks if your spouse is susceptible to airborne infections
3. A 9-1-1 information card by the telephone, on the refrigerator, or on a door. You may be confused and disoriented in a crisis. Another person may need to call 9-1-1 and not know all of the needed information. This should include the following:
    a. Your street address, apartment number, and closest cross street

   b. A callback number, in case emergency personnel have additional questions
   c. Your spouse's chronic medical conditions
   d. Your spouse's recent medical events
4. If your spouse has an out-of-hospital Do Not Resuscitate order (DNR), have it with the 9-1-1 information.

From the Survey

Most care partners did not have a grab-and-go bag ready for a trip to the ER.

What did you take to the emergency room during your spouse's most recent visit to an ER? (Check all that apply.)

	Percent
The DLB portfolio for your spouse.	34.4%
Your spouse's completed LBD Medical Alert Wallet Card	16.4%
The LBDA's fact sheet: Emergency Room Treatment of Psychosis	19.7%
Items to occupy your spouse's time while waiting.	18.0%
Items to occupy your time while waiting.	39.3%
A jacket or blanket to keep your spouse warm; ERs tend to be cold.	31.1%
A change of clothes for your spouse.	26.2%
A change of clothes for yourself.	9.8%
None of the above.	26.2%

Does your Spouse Need to Go to the ER?

Sometimes, you may know immediately that your spouse is facing a life-threatening condition (for example, loss of consciousness, breathing trouble, bleeding, or serious trauma). Calling 9-1-1 is clearly the best option for care that begins as soon as paramedics arrive. To help you decide if you should call 9-1-1, the American College of Emergency Physicians suggests that you answer the questions below. If the answer is yes to any of these, call 9-1-1.

- Is the condition life or limb threatening?
- Could the condition worsen quickly on the way to the hospital?
- If you move your spouse, will it cause further injury?
- Does he need skills or equipment that paramedics or EMT's can use right away?
- Would distance or traffic cause a delay in getting him to the hospital?

Other times, you may sense that your spouse’s condition warrants treatment, but you don’t know if it requires a trip to the ER. In those cases, contact his doctor, provide the symptoms, and ask if your spouse needs to go to the ER. Given the issues that can arise in the ER (e.g.: "long delays, discomfort, crowding, infectious viruses), it is good if you can avoid going there. However, don’t delay in calling your spouse’s doctor because it may be more serious than you think. You will be glad that you have coordinated with his doctor for how to contact her in an emergency – hopefully with a direct phone call.

If your spouse’s doctor is affiliated with a hospital, your spouse might be a direct admission to avoid going to the ER. Ask the doctor if the symptoms indicate that a hospitalization will probably be required. If so, request direct admission to the hospital.

If the doctor recommends that your spouse go to the ER, ask if you need to call an ambulance. If not, you, a friend, or family member can transport him in a car. An ambulance ride can be very traumatic for anyone, and even more disorienting and disturbing for someone with LBD – especially if the ambulance service does not allow you to accompany him. If his condition is not life-threatening, avoid using an ambulance. One advantage, however, of using an ambulance is that your spouse may be seen sooner at the ER than if you transport him.

Cost is another reason to avoid calling 9-1-1 unless it is absolutely needed. You, Medicare, and/or your insurance company will be billed for the ambulance services which can be quite costly. Furthermore, when you don’t use 9-1-1 services for non-emergencies, those services are available to others who do have a life-threatening emergency.

Ask the doctor to call the ER so that they expect your spouse. The doctor can give the ER staff information to use in making decisions about the needed care.

They will also know that you are accompanying your spouse as a member of his heath care team.

Your spouse's doctor may not think a trip to the ER or hospitalization is warranted. However, the doctor may think that your spouse should be seen by a doctor as soon as possible. If so, make an appointment to see the doctor within 24 hours or take him to a previously identified urgent care facility.

Calling 9-1-1

If you realize that your spouse has a life-threatening emergency, or your spouse's doctor tells you to call 9-1-1 for an ambulance, be prepared to make that call under stressful conditions. You can call from a land line or a cell phone with the major difference being that the dispatcher can identify your location from a land line but not from a cell phone. In either case, you will be asked for your location.

Stay with your spouse when you make the call. Let the 9-1-1 dispatcher take the lead with questions designed to obtain the information needed to get your spouse the right help as fast as possible. Don't interrupt the 9-1-1 dispatcher, follow all instructions, and be ready to answer questions such as the following:

- What is your location (complete address and cross streets)?
- What is a good call back number?
- Is your spouse awake and conscious?
- Is he breathing?
- Is he injured?

The American College of Emergency Physicians has identified significant warning signs of a medical emergency. These do not include every kind of sign or symptom that might indicate a medical emergency.

- Difficulty breathing, shortness of breath
- Chest or upper abdominal pain or pressure lasting two minutes or more
- Fainting, sudden dizziness, weakness
- Changes in vision
- Difficulty speaking
- Confusion or changes in mental status, unusual behavior, difficulty waking
- Any sudden or severe pain
- Uncontrolled bleeding
- Severe or persistent vomiting or diarrhea
- Coughing or vomiting blood
- Suicidal or homicidal feelings
- Unusual abdominal pain

- Is he in a dangerous spot or position where further injury could occur?
- Has he experienced a recent major medical event?
- Does he have a chronic medical condition?

Stay on the phone because the dispatcher may have more questions and may have information to give to you. Do not hang up unless the dispatcher tells you to do so. While waiting for the ambulance, stay calm, reassure your spouse, and make him as comfortable as possible. If first aid is needed, do only what you have been trained to do (e.g., CPR or wound care).

If another person is available, he or she can help by

- moving any furniture that would be in the way of the paramedics
- turning on lights if it is at night so that the ambulance driver can find your house more easily
- getting your LBD portfolio and grab-and-go bag
- calling others who you want to know about the emergency (including your spouse's doctor if you called 9-1-1 first)
- letting the emergency team in the door

If no one is with you, try to get someone to come by calling on another phone if available. If no one is with you, stay with your spouse to provide comfort, monitor symptoms, and stay on the phone with the 9-1-1 dispatcher. The other tasks can wait until the emergency team arrives.

What happens when the emergency team arrives?

Emergency medical technicians (EMTs) provide basic life support. A paramedic can provide more skilled treatment such as intravenous lines, cardiac rhythm interpretation, advanced airway treatments, etc. Often, there is one EMT and one paramedic on the ambulance emergency team.

When the ambulance arrives, you can help the emergency team provide the best care to your spouse. If he has an out-of-hospital Do Not Resuscitate order (DNR), give it to the EMT or paramedic. Have the materials in your LBD portfolio available. The American College of Emergency Physicians (ACEP) recommends that families prepare the materials that are included in your spouse's LBD portfolio. If this is well-organized, you can give the emergency team the information they need quickly.

The EMT or paramedic will ask your spouse some questions such as, "What is your name? What happened? How much pain do you have? Can you move?" They will also ask you questions to identify as quickly as possible what needs to be done:

- past medical history
- current medications
- allergies
- physician's name and contact information
- hospital choice
- when your spouse last ate
- when and what medications were last administered
- if unusual stressors have been present (e.g., infections, stress, exercise)
- and more.

After the emergency team has an idea of your spouse's problem, they will do a physical assessment to determine the extent of the problem and decide what needs to be done immediately. They will check his vital signs with a blood pressure cuff, stethoscope, and pulse oximeter. They may also use some type of heart monitor (e.g., ECG).

The emergency team will provide the initial care to stabilize your spouse. They may give him oxygen, medications, or fluids; stop any bleeding; stabilize your loved one's head, neck, and back; or perform other needed interventions. They should discuss all of these treatment options with you and your spouse. You can ask them not to do some things. For example, ask about any medication they may want to administer to avoid drugs that may cause adverse reactions in someone with LBD. If your spouse has an out-of-hospital DNR, show it to the emergency team, if you have not already, to prevent them from doing CPR. (Note: If you don't have the DNR, the emergency team is required to perform CPR if your spouse has stopped breathing.)

Once they stabilize your spouse, the emergency team will transfer him to a stretcher and move him to the ambulance.

Transportation to the ER

If your spouse is being transported to the ER by ambulance, the emergency team will alert the hospital to expect him. Depending on his condition, they will take him to your preferred ER or one they have determined will better meet his needs.

Ambulance services have different polices about whether a spouse can accompany the person being transported in the ambulance. If allowed, ride in the ambulance. You can help to keep your spouse calm, reassure him, and answer questions the emergency team might have. You will arrive at the ER room at the same time as your spouse to be able to assist with the transition from the ambulance to the ER. Be sure that you take the items you have at-the-ready, and be prepared for what might be a bumpy ride. The ambulance driver may or may not use the lights and sirens, but will use the safest speed to get your spouse to the ER. During the ride, the paramedic will monitor your spouse's condition, continue to provide emergency treatment, and communicate with the ER staff.

If your spouse is taken to the ER by ambulance, and you are not be allowed to ride along, you, a family member, or a friend will need to drive. Take your at-the-ready items in the car. If you are going to your preferred ER, set the destination in your GPS, but still follow the ambulance at a safe distance. If you are going to a different ER, get a complete address from the emergency team, put it in your GPS, and follow the ambulance to the ER.

If you have not called 9-1-1 and need to transport your spouse to the ER in a car, it is best if you have another person go with you. The person can drive while you monitor and comfort your spouse or vice versa. This person can also stay with you at the ER so that you can take breaks to use the bathroom or talk with a doctor without leaving your spouse unattended.

Use care in getting your spouse into the car, using the back seat if it is accessible so that one of you can be next to your spouse during the drive. Be sure that the seat belt is secure, that your spouse is warm enough, and adjust his position as needed. There may be a time when you will have to transport your spouse alone. In this case, use the front passenger seat so that you can observe and communicate with him.

At the ER

There are several stages to a visit to the ER:

- checking in
- triage (determining your spouse's priority for treatment based on the severity of his condition)
- waiting
- medical screening and treatment
- discharge (home or to the hospital)

At each stage, there are things for you do for your spouse. You are his voice to be sure that the ER staff get the information they need quickly and accurately. Your goal is to avoid the wrong procedure, medication, or conclusion. It is your job as the care partner to tell them what your spouse would want to happen.

<u>Checking into the ER.</u> Whether your spouse arrives in an ambulance or by car, an ER clerk will greet you and obtain and verify identification and other basic information, insurance, and medical history. This information will be entered into a computerized system. If your spouse has been to this ER before, his information in the system must be validated and updated.

- Start by letting the ER clerk know your role in the care of your spouse and that you have a medical power of attorney (MPOA) to make decisions.
- Inform the ER clerk that your spouse has LBD. Make sure that it is noted in the chart so that everyone your spouse sees is aware of this.
- Also, tell the intake person about your spouse's LBD medication sensitivities.
- Request instructions be written in the chart that antipsychotic medications should be avoided.

Provide a copy of your spouse's completed LBD Medical Alert Wallet Card and the LBDA's fact sheet: Emergency Room Treatment of Psychosis (see Section 3).

The clerk will need to enter all of your spouse’s medications. You can expedite this and increase the likelihood that it will be correct by providing the list of all of his medications from the LBD portfolio. Include a specific list of any medications to avoid due to past adverse reactions with notations as “allergies.”

Triage. Next, your spouse will be seen by a triage nurse who does a brief exam, takes vitals, and asks questions to determine how severe his condition is. The nurse will decide in what priority your spouse will be seen by an emergency room doctor. Patients are treated in the order of their clinical urgency.

Tell the triage nurse and each new person who sees your spouse about his LBD and the precautions that must be taken. This experience can be stressful for your spouse, so do all that you can to put him at ease.

Not all ERs use the same triage categories, but most are similar to the following:

Level	Triage Categories
1	Resuscitation: Immediate, life-saving intervention required without delay
2	Urgent: Stable, with multiple types of resources needed to investigate or treat (such as lab tests plus X-ray imaging)
3	Emergent: High risk of deterioration, or signs of a time-critical problem
4	Less Urgent: Stable, with only one type of resource anticipated (such as only an X-ray, or only sutures)
5	Nonurgent: Stable, with no resources anticipated except oral or topical medications, or prescriptions

Waiting. This may be the most difficult part of the ER visit. Your spouse may have to wait to be seen by an ER doctor while patients who are more critically ill are treated. Make sure that he is physically comfortable – either in the waiting room or in an ER bed. If it is cold, use ER warming blankets or one from your grab-and-go bag. He may doze off and sleep, which is fine. Otherwise, chose something from the grab-and-go bag to occupy his time.

If your loved one gets agitated or stressed, try one of the strategies that works at home: essential oils, music, massage, etc. Provide a drink or snack only if it has been approved by the ER nurse. There may be some tests that should not be done after eating or drinking. Monitor your spouse’s condition; if symptoms worsen or there is more pain, notify a nurse. If someone else has accompanied you, take a break to go to the bathroom, take a walk, or get a snack.

If the waiting room is loud and chaotic, it may be distressing to your spouse. Ask if there is a quieter place where you can wait. Explain that he is susceptible to the environment because of LBD, and you want to avoid any psychological or behavioral symptoms from emerging.

Don’t hesitate to advocate for your spouse, but do so without being obnoxious. As each new ER person interacts with your spouse, get his or her name – many have business cards that you can use to jot a note on. Use the notebook from your LBD portfolio to record every treatment and medication. If someone has accompanied you, that person can be your note taker.

<u>Medical screening and treatment</u>. When it is your spouse’s turn, an ER doctor will conduct a medical screening exam. Assist your spouse in answering questions. Facilitate the exam process by reassuring him about any of the procedures. He may need to have other exams such as blood work, an electrocardiogram (EKG), X-rays, or CT scans. He may need to see other doctors. Stay with him at all times unless the person who has accompanied you stays with him for a short time.

Ask questions about each test and procedure, taking notes so that you don’t forget. (Or, the person who has accompanied you can take notes.) Find out what the next steps are so that you can prepare your spouse for anything that might be disorienting or disturbing. Although all ER staff have been trained to wash their hands before touching each patient, sometimes they don’t do so – remind them nicely to wash their hands and to wear clean gloves. The last thing you want is for your spouse to get an infection from the ER!

If you think that your spouse is not being cared for correctly or there is some problem that isn’t being addressed, talk to the ER staff. If the issue is not taken care of, ask to talk with the attending physician, the patient advocate, or the nurse manager.

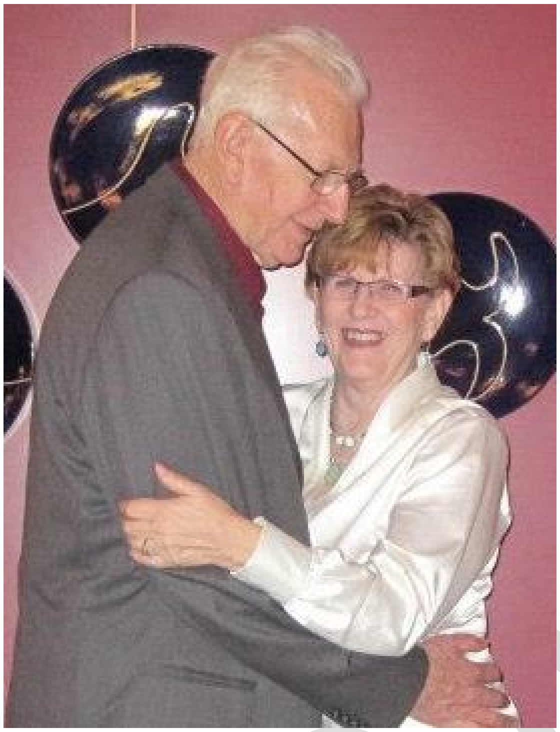
When all of your spouse's test results are available, an ER doctor will prescribe the treatment and care plan. Some actions may be started in the ER, some will be explained if you are taking your spouse home, and some might be for transfer to the hospital.

Discharge. Get copies of all of the test results and request that copies be sent to your spouse's LBD specialist and other doctors. If your spouse is going home, get written instructions on what needs to be done – and not done.

- When and what can your spouse eat and drink?
- What medications should he take, when, and how?
- What treatments do you need to do (e.g., wound care)?
- When should you schedule a doctor's follow-up appointment?
- What, if any, home healthcare is being arranged?

The discharge nurse should go over these instructions with you so that you are sure that you understand them completely. Don't be shy about asking questions or requesting more information.

8. Before, During, and After Hospitalizations



I followed the ambulance to the hospital. I pulled my hospital file from the glove compartment and followed the paramedics inside. I watched as they put an orange allergy band on Don's wrist, warning *No Haldol, No Benzo's*. I always feel better when that orange warning band is put on immediately. Don was admitted for observation. The hospital's protocol starts patients under observation, and the doctor in charge admits as an inpatient if necessary. The doctor explained *syncope* and Don's treatment plan, and fully admitted him as an inpatient. He was identified as a fall risk on his chart, and the regimen began. After three days, he felt better and was discharged. At home, we followed the discharge instructions for his medications, compression stockings, a wedge pillow, an appointment with his doctor, and continued PT. Pat and Don

The previous section gave you ideas to use before, during, and after trips to the emergency room. Sometimes, when your spouse has been in the ER, she will be discharged to go home. Other times, she will be discharged for transfer to a hospital. The hospital might be the one in which the ER is located, or it might be a different hospital. In some cases, she may have a direct or planned admission to the hospital without a trip to the ER.

People with dementia have an increased rate of hospitalization. This rate is even higher when they have comorbidities (other health problems). Thus, it is likely that your spouse will be hospitalized. You can be proactive by being prepared.

From the Survey

- About half (47%) of the spouses with LBD had been hospitalized.
- 20% stayed 1-2 nights; 42% stayed 3-4 nights; 15% stayed 5-6 nights.
- 57% had a hospitalist as their attending physician.
- 70% were fully admitted; 19% were admitted under observation (11% did not know admission status).

How to Select a Hospital

You may think because you have selected an ER that you have also selected a hospital. This is not always the case. You may have chosen an ER because it is close to where you live and it meets other important ER criteria. However, the ER hospital might not be the best one for your spouse. There may be another hospital, perhaps farther away, that can treat her LBD symptoms or other health conditions better.

Ideally, you will find a single hospital that can treat both your spouse's LBD and her other health problems. This is likely if you are near a large hospital, a teaching hospital, or a research center. Look for separate departments for the specialties that treat her conditions. Often, the more beds a hospital has, the more services it provides. Some hospitals have special departments for older adults, such as acute care for the elderly (ACE) units. All staff in these units are trained to care for older patients including those with dementia.

Start with her doctors – the PCP, LBD specialist, and other specialists. If they have affiliations with hospitals, consider those facilities. Being hospitalized is stressful. Your spouse – and you – will be less stressed if you already know the attending doctor at the hospital. However, many doctors are not affiliated with a hospital. Hospitalists manage the care within many hospitals and bring in specialists for consultation. If her doctors don't have hospital affiliations, ask them what hospitals they recommend for her and where they would take a loved one.

You can also ask friends, family members, and other trusted acquaintances about hospitals. What were their experiences when a loved one had needs similar to those of your spouse?

When you have identified one or more hospitals, ask the following questions. You can find answers to some of the questions online as noted.

1. Is the hospital accredited by the Joint Commission on Accreditation of Healthcare Organizations? Go to http://qualitycheck.org.

   From their website: "Quality Check allows consumers to:

   - Search for accredited and certified organizations by city and state, by name, or by zip code (up to 250 miles).
   - Find organizations by type of service provided within a geographic area. The results can be filtered by type of provider, setting of care, or patient population.
   - Download free hospital performance measure results by clicking on the Quality Data Download tab.
   - Print a list of Disease-Specific Care Certified Organizations."
2. How is the hospital rated by other organizations? You can find quality information about hospitals at these sites:
   - Centers for Medicare & Medicaid Services (CMS) at www.medicare.gov/hospitalcompare
   - Consumer Reports at http://www.consumerreports.org/health/doctors-hospitals/hospital-ratings.htm
   - The Leapfrog Group at http://www.leapfroggroup.org/56440
   - The U.S. News & World Report at http://health.usnews.com/health-news/best-hospitals/articles/2015/07/21/best-hospitals-2015-16-an-overview
   - Your state may have a hospital quality rating system online.
3. Does your spouse's LBD specialist or another of her doctors have privileges at the hospital? If so, the doctor can admit and treat her at the hospital. If not, a hospitalist and consultants will treat her.
4. Does the hospital accept your insurance: Medicare, Medicaid, and/or private hospitalization insurance?

5. Does the hospital have staff experienced with LBD and your spouse's other health conditions?
6. Does the hospital have a separate unit for the elderly and those with dementia?
7. Can your spouse have a private room? She needs a quiet, calm environment. Roommates and their guests can cause sensory overload.
8. Can you spend the night with your spouse? Nighttime activities in the hospital can cause problems for patients with LBD. Your presence can help her remain calm. If you can spend the night, will the hospital supply a recliner so that you will be able to sleep?
9. Will your spouse be comfortable at the hospital? Make an appointment to visit the hospital. Look at the rooms, observe the staff, and eat in the cafeteria.
10. How far are you willing to travel? Is this hospital within this distance?

What to Have At the Ready

You can have many of the same things at-the-ready for your spouse's hospitalization as you have for a trip to the ER. Have the following ready to go:

1. Your spouse's LBD portfolio - See section 3 for what should go into this portfolio.
2. Your spouse's eyeglasses, hearing aid, dentures, and other assistive devices (e.g., cane or walker).
3. A grab-and-go bag of items for you and your spouse:
    a. Toiletry items for you and your spouse: toothbrushes and toothpaste, comb, brush, wet wipes, deodorant, lotion, hand sanitizer, tissues, battery-operated shaver, etc.
    b. Items used to calm her, such as essential oils, family photos, favorite music, spiritual items, favorite pillow or blanket, etc.
    c. A change of clothes for you and your spouse
    d. Your spouse's slippers, PJs/nightgown, and robe (Check to see if the hospital will allow patients to wear personal clothing.)
    e. Items to occupy your time when your spouse is asleep or having tests or treatments: something to read, music with headphones, laptop or other portable electronic devices, etc.
    f. Phone and charger

g. Money for vending machines
h. Snacks and beverages for yourself. Your spouse can have these if the hospital allows outside food and drink and if she is not on a restricted diet.
i. Do NOT bring valuables such as cash and jewelry.

Being Admitted to the Hospital

There are several ways that your spouse can be admitted to the hospital:

1. Transfer from an emergency room at the same or a different hospital.
2. A direct admission in an emergency arranged for by one of her doctors who is on staff at the hospital.
3. A planned admission with arrangements made days or weeks in advance.

The admission process is about the same for all types of admission. You will go to the admissions office where a clerk will ask you and your spouse a series of questions and have you complete and sign several forms. If you have a medical power of attorney (MPOA), you may answer the questions and sign the forms. You have the needed information available in the LBD portfolio. If your spouse has a planned admission, you might be able to complete some of the paperwork ahead of time, perhaps electronically. If she has been a patient in the hospital in the past, you will need to confirm that the information in the electronic medical record (EMR) is still correct, and update it if her conditions or medications have changed.

Be ready to provide

- your spouse’s name, address, date of birth, telephone number, social security number, and the name and address of whom to contact in case of an emergency
- her government-issued photo identification (e.g., Driver’s license or photo ID from the Department of Motor Vehicles, passport, US military ID card)
- information and documentation for her insurance coverage
- the names of her physicians and contact information for them

- copies of documents from the LBD portfolio:
    - Advance directive/living will
    - Medical power of attorney (MPOA)
    - Do Not Resuscitate order (DNR) – Your spouse's doctor will order an in-hospital DNR. Not everyone will have a DNR.

You will need to read and sign several forms:

- General consent agreement
- Consent for surgery or other special procedure(s)
- Agreement to pay for services not covered by Medicare, Medicaid, or private health insurance
- HIPAA form

The admission clerk will prepare an identification wristband. Check the information on the band closely for accuracy. The hospital staff should check the ID band before every test, procedure, and medication administration.

When you have completed the clerical work, a patient escort will take you and your spouse to the hospital room. A nurse will usually greet you and ask your spouse to change from street clothes to her bedclothes or a hospital gown. The nurse will take your spouse's vitals (temperature, pulse, respiratory rate, and blood pressure) and either weigh her or ask for a weight to record.

The nurse will ask a series of questions and collect information to put into the electronic medical record (EMR). Use the forms and information in the LBD portfolio to provide complete information.

- Answer questions about your spouse's
    - current health and the reasons for coming into the hospital
    - personal health history
    - family health history
    - general health information, such as bowel regularity
    - complete medication information
    - allergies (drug, food, airborne, etc.)

- Provide information about the following, and be sure that it is noted in the EMR and on her chart:
    - Your spouse’s LBD diagnosis
    - Medications to be avoided (e.g., anticholinergics, benzodiazepines, and antipsychotics)
- Give the nurse the following:
    - Her LBDA medical alert card
    - Information on LBD for the staff
    - Provide specific information about your spouse to assist the staff in meeting her needs
    - How much assistance she needs for activities
- Information to make her a person and not just a patient
    - family information, living situation, major life events
    - work, leisure, and spiritual history
    - Daily schedule and patterns
    - Favorite foods, beverages, music, and other activities
- Possible psychological and behavioral symptoms, what causes them, how to avoid them, and how to treat them without medication
- Inform the nurse that your spouse should receive ***no*** treatment or medication without your approval. This is within your rights with a medical power of attorney.

Observational Outpatient or Inpatient Status?

Did you know that even if your spouse stays in the hospital overnight – or several or more nights – her hospital status might be as an outpatient under observation? As long as she receives the needed services while hospitalized, what difference does this make?

First, if the hospital classifies her status as an outpatient under observation, you may be charged personally for services that Medicare and/or your other health insurance would pay for with an inpatient admission. Typically, you will pay a larger portion of the bill out-of-pocket for observation services than you would have paid for inpatient services – even though the services are identical.

- As an inpatient, Medicare Part A (hospital insurance) covers all inpatient hospital services after you pay a one-time deductible for all hospital services for the first 60 days of hospitalization. Medicare Part B (medical insurance) pays for most doctor services with you paying 20% of the Medicare-approved amount for doctor services after paying the Part B deductible.
- As an outpatient on observation status, the payments are from Medicare Part B, and you are financially responsible for a 20% copayment for *each* outpatient hospital service (all tests and services) she might receive. In addition, you would need to pay for any oral or IV medication. This adds up very quickly with the often-expensive tests and medications.

Second, and perhaps more significantly, if she needs to go to a skilled nursing facility (SNF) after the hospitalization, Medicare would not pay for those SNF services. After a three-day inpatient stay, however, Medicare would pay 100 % for the first 20 days after which you would need to pay $157.50 for days 21-100 and full payment after that. If you have supplemental insurance, it would likely pay the balance for days 21-100, but not after that.

Obviously, unless you and your spouse's doctor agree that there is cause to admit her for observation only, it is best to have a full inpatient admission. So what can you do to make this happen?

1. At the time of admission, discuss her admission status with the admitting doctor and request full inpatient admission.
2. Confirm her admission status every day as it can be changed at any time.
3. If she is admitted under observation status, ask the doctor to reconsider or refer the case to the hospital committee that decides admission status.
4. If her LBD specialist or other doctor is not treating her at the hospital, discuss whether the observation status is justified and, if not, ask him or her to explain to the hospital doctor why she should be admitted as an inpatient.

5. If the hospital won't change her status from outpatient to inpatient, appeal the observation status. An internal committee or outsourced advisory third party may review the appeal process. Ask her case manager, patient advocate, or hospital ombudsman about this.
6. If she needs to go to a skilled nursing facility and does not meet the three-day hospital inpatient criterion for Medicare to pay, formally appeal the decision.
7. If she needs continuing care and Medicare won't pay for an SNF, ask about other services that Medicare would pay for: home healthcare (nursing, physical therapy, occupational therapy, speech therapy, and home health aide) or a rehabilitation facility.

Hospital admission can be a very confusing matter. For more detailed information on how Medicare covers hospital services, including premiums, deductibles, and copayments, visit https://www.medicare.gov/pubs/pdf/10050.pdf to view the *Medicare & You* handbook. You can also call 1-800-MEDICARE (1-800-633-4227). For more information about how Medicare covers care in an SNF, visit https://www.medicare.gov/Pubs/pdf/10153.pdf to view *Medicare Coverage of Skilled Nursing Facility Care*. See also the website of the Center for Medicare Advocacy for their suggestions about observation status (http://www.medicareadvocacy.org/medicare-info/observation-status/).

From the Survey

Do you understand the difference between being fully admitted and admitted for observation and the implications for hospitalization billing and costs to you AND for costs of skilled nursing if needed after hospitalization?

	Percent
No	18.5%
Somewhat; I need to know more	41.3%
Yes; I fully understand	40.2%

During your Spouse’s Hospitalization

<u>Get to know the hospital staff.</u>

1. Meet the attending physician – the doctor who is in charge of your spouse’s care in the hospital. Write down the doctor’s name, how to contact him or her, and when the doctor makes rounds. Be with your spouse when the attending physician and other doctors come to her room. Ask questions, write down information, and discuss issues with them.
2. Meet all other doctors who interact with your spouse as consultants and specialists. Get their cards or write their names in your notebook. Ask questions.
3. Introduce yourself to the nurses on every shift. Write their names down. The nurses can be your main resource. Be sure that they understand LBD. If they don’t, give them printed information about LBD. Tell them how LBD affects your spouse and what they should watch for.
4. Get to know other hospital staff: aides, orderlies, therapists, technicians, patient transporters, cleaning staff, etc. Each of these plays a role in your spouse’s well-being. Be cordial and appreciative of what they do.

<u>Keep your spouse safe.</u>

Be sure that staff members check your spouse’s ID information before each test, procedure, medication, surgery, etc.

1. Help prevent her from getting an infection by making sure that everyone washes their hands before touching her. Staff members should also use new disposable gloves, and clean any equipment that they have used with other patients. If they don’t, remind them politely to do so.
2. If she is at risk of falls, this should be noted on her chart, posted in the room, and on a separate bracelet. You or someone else should stay with her at all times.
3. If she is immobile in the bed, take actions to avoid bedsores. Be sure that someone repositions her several times a day.
4. Ask friends and relatives not to visit her if they have any contagious illness.
5. Be sure that she remains hydrated. Check to see that fresh water is always within reach. Help her drink fluids throughout the day.

6. Monitor what she eats. The menu choices should match the diet prescribed by the doctor. Select menu items that you know she is more likely to eat. Ask for snacks if she is not eating her meals. As needed, help her eat.
7. Your spouse needs to go to the bathroom regularly. Make sure that she is urinating and having bowel movements.
8. If she is incontinent, ask an aide to change her disposable, absorbent underwear as soon as it is wet.

<u>Educate the hospital staff about LBD and your spouse.</u>

1. Nurses, aides, and even doctors may not know much about LBD. You can help inform them.
2. Have printed copies of materials from the LBDA handy to give to hospital staff.
3. Provide links to resources on the Internet.
4. Discuss LBD with hospital staff.
5. Let the staff know about how LBD affects your spouse. Tell them what they need to watch for, do, and not do.
6. Humanize your spouse so that she is a person not just a patient with a set of symptoms.
7. Provide written information about who your spouse is: What does she like to be called? What are some interesting highlights about her family, work, hobbies, and other interests? What are her likes and dislikes?

<u>Keep your spouse calm and comfortable.</u>

1. Minimize the noise, distractions, and chaos of the hospital environment. Keep the room door shut, turn off the television, soften the telephone ringer, and ask someone to turn off the intercom.
2. Make the hospital room feel familiar to your spouse with photos, flowers, favorite pillow or blanket, and preferred music.
3. Use the techniques that work at home to keep her from being agitated or to reduce anxiety. Use

touch and gentle massage with essential oils such as lavender. Play calming music. Talk in a calm, reassuring voice. Read aloud, pray with her, or sing to her.

4. Tell and show the hospital staff what they can do to avoid psychological and behavioral symptoms of LBD.

<u>Monitor and report your spouse's symptoms</u>.

1. Watch for confusion, agitation, hallucinations, and other behavioral symptoms. A medical problem such as fever, infection, medications, or dehydration may be the cause of these symptoms.
2. Let the nurse or doctor know if your spouse seems suddenly worse or different. You are likely to recognize changes before anyone else.
3. Look for signs that she is in pain: creased brow, gritted teeth, clenched fists, thrashing about, difficulty breathing, moaning, crying, or grimacing.
4. Watch for signs or symptoms of skin breakdowns or infections: red spots, blisters, skin warm to the touch, bedsores, etc.
5. Be alert to problems with bodily functions such as diarrhea, constipation, or low urine output.

<u>Assist with your spouse's care</u>.

1. Your spouse will feel more comfortable if you take part in her care. The staff will welcome your assistance. Helping the staff will allow them to get to know you and your spouse better. Discuss with the staff what you can do to be a partner in your spouse's care.
2. Help her eat, open containers, patiently allow time to complete a meal, and assist to the extent needed.
3. Assist with bathing and hygiene. Be present when others care for her to provide hints on how to do tasks and to reassure her.
4. Find out where to get snacks, water, extra blankets, etc. Get those items when she needs them.
5. You won't be able to give her medications, but you can make administering them go smoothly. Tell the nurse how your spouse usually takes medications. Reassure her if she resists taking medications.

Ask questions, take notes, and get information.

1. If there is any aspect of your spouse's care that you don't understand, ask questions.
2. Write down questions about her diagnoses, condition, treatments, medications, etc. as you think of them. It is easy to forget what you want to ask.
3. Take notes on everything.
4. Keep track of all instructions.
5. Ask to look at her chart on a regular basis.
6. Obtain copies of all test reports.

Take care of yourself.

1. Get rest. Try to sleep while your spouse is sleeping. Have a friend or family member relieve you so that you can get uninterrupted sleep.
2. Remember to eat. Make nutritious choices from the hospital cafeteria or have friends bring you meals. Have healthy snacks on hand.
3. Fill time with relaxing activities: read a book, listen to music, play a game, etc.
4. Talk to a confidant about your concerns and fears. Speak with the hospital social worker or chaplain.
5. Take breaks when someone else can be with your spouse. Go for a walk, get some fresh air, take deep breaths, do relaxation techniques, visit the chapel, etc.

Discharge

Medicare defines discharge planning as "a process used to decide what a patient needs for a smooth move from one level of care to another." Plan early for your spouse's discharge. Meet with the hospital discharge planner and social worker in anticipation of your needs when you take your spouse home. Will you need home health services (a nurse, an aide, physical therapist, occupational therapist, or speech therapist)? Will you need equipment (wheelchair, walker, hospital bed, commode, shower bench, Hoyer lift, etc.)? Is it likely that she will need follow-up care before going home (e.g., at a skilled nursing or rehabilitation facility)?

Be sure that staff understands your spouse's physical and mental capabilities and your ability to care for her. Let them know if you are concerned about taking care of her at home. You want them to order the appropriate help as part of the discharge plan. A doctor makes the final discharge decisions and signs the discharge papers.

The discharge plan should have these elements:

- Evaluation of your spouse by a doctor or other qualified person
- Discussion with you and your spouse
- Planning for going home or to another facility
- Reconciliation of medications
- Training or other support for you, as needed
- Referrals to home healthcare agency or other support organizations
- Arrangements for follow-up appointments or tests

For a comprehensive discussion, read *Hospital Discharge Planning: A Guide for Families and Caregivers* at https://www.caregiver.org/hospital-discharge-planning-guide-families-and-caregivers.

You should get a printed discharge document that includes the following:

- Your spouse's condition and what problems or conditions to watch for at home
- Information about what recommended discharge services Medicare or insurance will pay for (e.g., rehabilitation, skilled nursing, home health, etc.)
- Arrangements for home health services, equipment rentals, or home modifications (as needed)
- Referral to community-based services (e.g., adult daycare services or case management)

- Medication reconciliation that compares all medications taken before admission and all medications prescribed for after discharge. This is to avoid duplications, omissions, or adverse effects.
- A complete list of medications with instructions on when and how to take each medication
- Summary of any training you received for care of your spouse
- Information about follow-up appointments: locations, phone numbers, dates, and times
- A 24-hour phone number you can call to speak with a healthcare professional about any concerns you have

From the Survey	Percent
Stayed with your spouse most of the time to provide emotional support, manage any behavioral issues, and prevent falls.	75.9%
Introduced yourself to the nurses for each shift.	72.2%
Met the attending doctor and discussed such things as the reason for your spouse’s admission, the plan for his/her treatment, anticipated length of stay, importance of all staff being knowledgeable about your spouse’s DLB.	68.5%
Complemented/verbally acknowledged members of the hospital staff for the care provided to your spouse	63.0%
Found out what time of day the doctor makes rounds so you could plan to be present.	53.7%
Spoke with a social worker.	51.9%
Asked to be notified if any new medications were ordered, any standing medications discontinued, or other standing orders were modified.	50.0%
Assisted the staff in tasks with your spouse (e.g., got warm blankets, got allowed snacks and beverages from where these are kept, raised and lowered the bed, assisted your spouse during meals, helped staff turn him/her in bed).	50.0%
Used the hospital’s free Wi-Fi service.	50.0%
Spoke with the charge nurse or the nursing director to resolve a problem.	48.1%
Invited the nurses to call you with any questions or concerns, regardless of the time.	46.3%

From the Survey	Percent
Kept notes on your spouse’s daily progress, new medications, treatments, and other medical care (either written or electronically on a laptop, tablet).	37.0%
Let the staff know when something was agitating your spouse so that changes could be made (less noise, fewer distractions, fewer sleep interruptions, fewer visits and questions by students in a teaching hospital).	37.0%
Enlisted family members and/or friends to stay with your spouse when you could not be there.	33.3%
Wrote down the names of your spouse’s primary nurses and physicians and their contact information.	31.5%
Let hospital staff know any helpful tips about feeding or bathing your spouse.	31.5%
Verified that the information you provided during the intake/admission process was completely and accurately entered into the hospital’s EMR	29.6%
Stayed with your spouse overnight in the hospital room.	27.8%
Asked for a printed copy of any test reports.	25.9%
Prior to any surgical procedures, met with the anesthesiologist to discuss anesthesia and sedatives that pose dangers to people with DLB.	25.9%
Alerted the staff to disturbing changes in behavior that might signify the need for addition of medications or the discontinuance of medications.	24.1%
Used your power of attorney to refuse drugs you believe to be harmful.	14.8%
Visited the hospital chapel.	14.8%
Asked to see your spouse’s chart.	11.1%
Asked everyone who came in contact with your spouse to wash their hands before touching your spouse to help prevent the spread of hospital infections.	9.3%
Spoke with a patient advocate or ombudsman to resolve a problem.	7.4%
Hired a private-duty nurse or aide to stay with your spouse when you could not be there.	1.9%
None of the above.	1.9%

After Hospitalization

- You and your spouse will be glad to be home, but the days and weeks following a hospitalization can be challenging. You want to prevent her return to the hospital. Here are actions you can take to make the transition from hospital to home as smooth as possible.
- Watch your spouse carefully for changes in status. Be aware of possible adverse drug effects.
- Call the 24-hour phone number anytime you have a concern.
- Follow the instructions in the discharge plan carefully.
- Make note of any questions or issues you want to discuss with the healthcare professional, who should call you within 24–36 hours after discharge.
- Get help from family and friends. You will be tired and have much to do. Helpers can do household chores, cook, run errands, and spend time with your spouse.
- Help your spouse to get comfortable at home again. Return to the familiar pre-hospitalization schedule and activities.
- Get instructions on any new equipment delivered to your home.
- If home healthcare is part of the discharge plan,
    - coordinate with the home healthcare agency to plan a schedule that best fits your spouse’s needs.
    - provide information about LBD to staff who likely won’t know much about LBD.
    - monitor the staff. You want to be satisfied with what the nurse, aide, and therapists do with your spouse. If you are not satisfied, talk to the agency.
- Keep all follow-up appointments with doctors and labs. If your spouse has to miss an appointment, reschedule it as soon as possible.


attending physician
hospital
assist
safety
ER transfer
planned admission
educate
direct admission
take care of self
follow-up
hospitalist
grab-and-go bag
stay
discharge
nurses
meets your criteria
LBD portfolio
observation
inpatient
monitor

9. Handling Problems and Conflicts with your Spouse’s Healthcare Team

After an attempted suicide, Douglas was committed to the hospital where I met with the psychiatrist a few days later. I was dissatisfied with his care in the mental health unit and believed that the staff lacked experience in dealing with LBD. I told Dr. Singh that this was not the place for Douglas and I wanted him at home with me. Douglas was upset at the prospect of being confined for two more weeks, and I was upset that Haldol had been prescribed for agitation. When I asked the nurse not to administer it as it had serious negative effects, she replied, “All drugs have side effects.” Dr. Singh said he was aware of how dangerous Haldol could be, and apologized several times for how poorly the situation had been handled. I gave him three packages of information on LBD and Haldol to share with his staff. He thanked me and said he would do so. The next day, Douglas was released home to my care. – Sandra and Douglas

You have done your best to find the right doctors; worked to establish positive relationships with them; tried to communicate with them effectively; and been an engaged care partner during office visits, trips to the ER, and hospitalizations. Still, you may encounter problems and conflicts. These can range from small one-time incidents that you can handle easily right away to serious, even life-threatening, events that call for formal complaints.

Provide Feedback

Most doctors welcome information that lets them know how they and their staffs are doing from their patients’ perspective. This means that you need to let healthcare providers know the good as well as the bad about office visits, the quality of care your spouse receives, and your communication with doctors and their staffs. Consider commenting on such things as how friendly, helpful, and organized the office staff are and how well the doctor listens, diagnoses, explains, and includes you as a partner.

It is especially important to let the doctor know about anything that had, or could have had, a negative impact on your spouse's health. You need to address errors in prescriptions, laboratory tests, instructions for home care, ER or hospital procedures, and other potentially dangerous mistakes.

Often, the best way to solve a problem and prevent it from happening again is to deal with it as soon as possible after it happens face-to-face with the doctor or other member of the healthcare team. When you have a concern, talk directly to the person involved (the doctor, nurse, receptionist, aide, etc.). Be specific about what happened and what your expectations are.

Let's say that the LBD doctor runs very late, spends too little time with you and your spouse, and appears distracted during the visit. You might say, "I understand that you may need to spend more time than expected with another patient; however, after we have waited for more than an hour, I expect that you will spend a reasonable amount of time with us and give us your full attention. We appreciate it when you take the time to do a thorough examination, listen to our issues, and discuss the treatment plan. " This gives the doctor the opportunity to explain, apologize, and take corrective actions.

If you and your spouse have a good relationship with the doctor, calling his or her attention to a problem gives all of you the opportunity to resolve it in a friendly way. You don't have to get others involved, anger or embarrass the doctor, or damage your relationship.

If the same thing happens repeatedly, however, provide detailed written feedback to the doctor. For the example above, you would include the dates and times of the scheduled visits, how long you had to wait each time, how much time the doctor spent with you, the doctor's lack of attention during the visit, and the impact this had on your spouse and you. Let the doctor know your expectations and perhaps make suggestions. For example, you might indicate that other patients are likely

experiencing the same frustrations but not voicing them, and suggest that the doctor modify the way in which the office staff schedules patients.

There are other ways to provide feedback. If the doctor or his or her physician practice has patient feedback forms, register your satisfaction and concerns using this delivery method. If the doctor does not have feedback forms, you can grade the doctor and the staff using an online form, print the form, and mail it directly to the doctor. See the DiagKNOWsis Doctor's Report Card at http://diagknowsis.org/reportcard/reportcard2014.htm.

There are also online sites to post doctor ratings and reviews for others to see. These were suggested as a source of information about doctors in Section 4, Finding an LBD Specialist. A few are

http://www.HealthGrades.com

http://www.RateMDs.com

http://www.Vitals.com

Doctors want a good reputation and know that people use these sites when they look for a new doctor.

File a Complaint

If you cannot resolve a problem directly with the doctor, you can file a formal complaint. Some formal complaints might solve the problem, and your spouse can continue to see the doctor. Other complaints are more serious, and it is likely that in addition to filing a formal complaint, you will need to find a new doctor. Behavior that results in a medical error, violates confidentiality, indicates that the doctor may be impaired (e.g., by alcohol, drugs, or medical condition), or abuses or intimidates you warrants a formal complaint – and a change of physician.

The practice manager. Many doctors belong to a group practice that has a manager and perhaps a committee that handles complaints. Start by writing a letter of complaint that

- is to the point and brief
- contains facts about what was done or not done

- outlines the effects on your spouse
- lets the person know what your expectations are for follow-up
- includes information about you and your spouse

This may be sufficient to solve the problem, and you won't have to escalate your complaint to a higher level. If the issue is not resolved or your confidence in the doctor cannot be restored, you will need to find a new doctor.

You may want to file a formal complaint with one of the agencies outlined below. If the complaint concerns something that could cause harm to other patients, you want the appropriate agency to know about it and take action.

Your state medical board. If you have a complaint about a specific doctor, nurse, or other care provider, go to your state medical board with issues such as unprofessional or unethical care, incompetent practice, practicing without a license, etc. You can find a directory of state medical boards at http://www.fsmb.org/state-medical-boards/contacts.

Medicare. You can file a complaint, also called a grievance, if you have a concern about the quality of care or other services your spouse gets from a Medicare provider. Consider filing a complaint if one or more of his Medicare rights and protections has been violated: These include

- protecting him when he gets health care
- making sure he gets the health care services that the law says he can get
- protecting him against unethical practices
- protecting his privacy

The Medicare website has links and instructions for how to file different types of complaints.

To file a complaint about a doctor, hospital, or provider, follow the directions at https://www.medicare.gov/claims-and-appeals/file-a-complaint/doctor-hospital-or-provider/complaints-about-providers.html

- Complaints about improper care or unsafe conditions
- Complaints about hospital conditions
- Complaints about your doctor

To file a complaint about the quality of care, contact the Beneficiary and Family Centered Care Quality Improvement Organization (BFCC-QIO). You can find the contact information at https://www.medicare.gov/Contacts/#home. These complaints can be about the following:

- drug errors
- unnecessary or inappropriate surgery
- unnecessary or inappropriate treatment
- not getting treatment after your spouse's condition changed
- getting discharged from the hospital too soon
- incomplete discharge instructions and/or arrangements
- his health or drug plan
- customer service
- access to specialists
- improper care or unsafe conditions
- hospital conditions
- his doctor
- home health agencies

In-hospital personnel**.** When problems arise in the hospital, start with the person concerned, ask a nurse for assistance, talk with the social worker or chaplain, or go to the hospital's patient advocate or ombudsman. Hospitals employ patient advocates to help patients and their families navigate the healthcare system and handle complaints. If talking to one of these people does not resolve the issue to your satisfaction, find out how you can take your concern to the hospital's ethics committee.

Most doctors and other members of the healthcare team in the hospital want to provide your spouse with the care that he needs. It is likely that they will work with you to solve the problem to your satisfaction, and you will continue your good relationship. There may be times, however, when a dispute is not settled to your satisfaction and you need to escalate your complaint to one of the following.

State health department. If you have a complaint about a hospital, clinic, or other facility, your state health department may be the place to go. Report facilities that are not safe, do not have handicapped accessibility, and have problems with temperature control, food quality, or cleanliness.

The Joint Commission. The Joint Commission receives and processes complaints about hospitals and other facilities it accredits. You can report a patient safety incident online at https://apps.jointcommission.org/QMSInternet/IncidentEntry.aspx.

Law enforcement. If you think that a doctor has done something illegal, contact a local law enforcement agency.

A lawyer. If you want to sue a doctor for malpractice that resulted in serious incapacitation or death to your spouse, consult with a medical malpractice attorney to file a lawsuit.

Finding a New Doctor

Sometimes, despite your best efforts, problems aren't solved and your relationship with your spouse's doctor is beyond repair. Dealing with problems and complaints is time-consuming and stressful, and your physical and emotional resources are better spent in the direct support of your spouse.

Once you decide that changing doctors is the right thing to do, follow the recommendations for finding a doctor in Section 4 of this guide. If the doctor you want to replace has not done harm to your spouse or acted unethically, don't sever that relationship until you have found a new doctor. Your spouse may need medical treatment before you find a replacement, and you don't want to be without a specialist.


state health department
problems
written
state medical board
Medicare
conflicts
formal complaint
Find a new doctor
in-hospital personnel
feedback
practice manager
The Joint Commission
lawyer
face to face
law enforcement

If you are a healthcare professional, when you have finished reading the Guide, or even if you have read only portions of it, please complete the survey at

https://www.surveymonkey.com/r/Professional-CPG

If you are a care partner for a spouse with LBD, when you have finished reading the Guide, or even if you have read only portions of it, please complete the survey at

https://www.surveymonkey.com/r/CarePartner-CPG

We will use your comments, suggestions, and other feedback to revise the Guide. Your opinions matter to us and will help us to improve this resource.

Please complete the survey by February 1, 2016.

Thank you,

Rosemary, Jeff, and Pat

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