

## CURE PSP MIDWEST FAMILY CONFERENCE SUGGESTED BOOKS AND RESOURCES

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Unfortunately, few books have been written specifically about Progressive Supranuclear Palsy and the other Parkinson's-plus disorders. However, many Parkinson's disease (PD) publications contain at least some information about PSP and related disorders. Therefore, I encourage you to take a look at the PD literature as well as materials about the less common movement disorders such as PSP.

Diagnosis-related books cover many different perspectives, styles, and topics. In your effort to select the "right" book – one that will resonate with your particular life situation, disease stage, role, or question – think about whether you want to learn about medical facts, "helpful hints," another patient's personal experience, a caregiver's experience, resources, or exercise. This will help you to focus your search.

I hope you find the following list of books and resources helpful to you now, and over time.

### **Last Dance at the Savoy: Life, Love and Caring for Someone with Progressive Supranuclear Palsy, b Kathryn Leigh Scott**

*Last Dance at the Savoy* is both a personal story about Scott's husband Geoff Miller, the founding editor of *Los Angeles* magazine, who lived life fully despite having PSP, as well as a sharing of her insights on dealing with the day-to-day issues of caring for him. Scott "often yearned for someone to figuratively take my hand and walk with me through the difficult times; I hope through this book I can reach out to you with encouragement and practical advice." *Last Dance at the Savoy* includes information about resources, support organizations, research studies, products and equipment, caregiving publications, and family conferences. A percentage of royalties from *Last Dance at the Savoy* are donated to CurePSP.

### **Saving Milly: Love, Politics, and Parkinson's Disease, by Morton Kondracke**

With the same attention to detail that distinguished his political commentary, Morton Kondracke chronicles his wife's 13-year struggle with Parkinson's disease, and his caregiver experience. He also provides unvarnished accounts of the battles among disease activists who must compete for limited federal research funds. This book is not only a vibrant, loving, and candid portrait of the indomitable Millicent Martinez Kondracke. It also depicts the determination of her caregiver husband, and his undying hope that research will provide a breakthrough.

### **Finding Meaning with Charles, by Janet Edmunson**

The author is a noted speaker on caregiving. While emphasizing the importance of helping a loved one to cope with illness with dignity and a positive outlook, she also addresses the emotional and physical challenges that caregivers face.

### **You Me and PSP: Cilla's Biography by Steve Dagnell**

As the term "biography" suggests, this book presents the patient's perspective. Cilla shows how living with PSP affected her. Cilla hoped that, by making her experiences public, she could help others.

### **The Comfort of Home for Parkinson Disease: A Guide for Caregivers, by Maria Meyer**

This comprehensive guide to the day-to-day issues confronted by Parkinson disease patients and their caregivers covers every caregiving stage. The book is illustrated and easy to read. It includes discussions about the decision to provide home care, preparing the home, assisting with daily activities, financial management, and strategies for avoiding caregiver burnout. The guide also offers tips on equipment, travel, loss of motor skills, and communicating effectively with physicians.

CurePSP: [www.psp.org](http://www.psp.org)

Disability Attorneys: [www.nationaldisabilitylawyer.com](http://www.nationaldisabilitylawyer.com), and [www.lawinfo.com](http://www.lawinfo.com)

Driver Assessment: Association for Driver Rehab Specialists [www.adednet](http://www.adednet)

Exercise Resources:

- National Institute on Aging: [www.nia.nih.gov/exercisebook](http://www.nia.nih.gov/exercisebook)
- American Physical Therapy Association: [www.apta.org](http://www.apta.org)

Federal Transit Administration: [www.fta.dot.gov](http://www.fta.dot.gov)

Healthcare Directives:

- Family Caregiver Alliance: [www.caregiver.org](http://www.caregiver.org)
- Your state medical society
- American Bar Association: [www.americanbar.org](http://www.americanbar.org)
- Commission on Aging with Dignity:  
[www.agingwithdignity.org](http://www.agingwithdignity.org)

Insurance: [www.medicare.gov](http://www.medicare.gov)

Mental Health Info Center: [www.mentalhealth.samhsa.gov](http://www.mentalhealth.samhsa.gov)

National Association of Area Agencies on Aging: [www.n4a.org](http://www.n4a.org)

National Institute of Neurological Disorders and Stroke:

[www.ninds.nih.gov](http://www.ninds.nih.gov),  
<https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Progressive-Supranuclear-Palsy-Fact-Sheet>

Nursing Home Information: [www.medicare.gov/NHCmpare](http://www.medicare.gov/NHCmpare)

Social Security Disability: [www.ssa.gov](http://www.ssa.gov)

Veteran's Administration: [www.va.gov](http://www.va.gov), [www.benefits.va.gov](http://www.benefits.va.gov)

**SELF-ASSESSMENT FOR CAREGIVERS  
DO YOU TAKE CARE OF YOURSELF?**

Rate each item below from 1 (Almost Always) to 5 (Never) according to how much of the time each statement applies to you.

1 = Almost Always, 2 = Frequently, 3 = Occasionally, 4 = Rarely, 5 = Never

- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| 1. I exercise on a regular basis.  | 1 | 2 | 3 | 4 | 5 |
| 2. I make and keep preventive and necessary medical and dental appointments.                         | 1 | 2 | 3 | 4 | 5 |
| 3. I have a job or regular volunteer activity that is gratifying.                                    | 1 | 2 | 3 | 4 | 5 |
| 4. I do not use tobacco products.  | 1 | 2 | 3 | 4 | 5 |
| 5. I do not use alcohol or drugs.  | 1 | 2 | 3 | 4 | 5 |
| 6. I get an adequate amount of sleep each day.   | 1 | 2 | 3 | 4 | 5 |
| 7. I have a hobby or recreational activity I enjoy and spend time doing.                             | 1 | 2 | 3 | 4 | 5 |
| 8. I eat at least two to three balanced meals a day.   | 1 | 2 | 3 | 4 | 5 |
| 9. I have at least one person in whom I can confide (tell my problems, discuss my successes).        | 1 | 2 | 3 | 4 | 5 |
| 10. I take time to do things that are important to me (e.g. church, garden, read, spend time alone). | 1 | 2 | 3 | 4 | 5 |
| 11. I do not have problems with sleeplessness or anxiety.  | 1 | 2 | 3 | 4 | 5 |
| 12. I have personal goals and am taking steps to achieve them.                                       | 1 | 2 | 3 | 4 | 5 |

**TOTAL SCORE:** (Add the numbers) \_\_\_\_\_

**INTERPRETATION:**

12-24 – You are doing an excellent job of taking care of yourself.

25-36 – You have some room for improvement.

37-48 – You are doing a poor job of taking care of yourself and are at moderately high risk for personal health problems.

48-60 – You are at extremely high risk.

Adapted from “Checklist for Caregivers: Do You Take Care of Yourself?” Bass, D.S. 1990, *Caring Families: Supports and Interventions*, p. 35, National Association of Social Workers.