

# SEATTLE COMMUNITY SUPPORT OPTIONS FOR INDIVIDUALS WITH APHASIA AND THEIR FAMILIES

## The University of Washington Speech and Hearing Clinic

- Individual and group aphasia therapy at a reduced rate.
- Call Megan Caldwell, Clinical Instructor, at (206) 543-0094.
- [http://depts.washington.edu/sphsc/clinic\\_about.htm](http://depts.washington.edu/sphsc/clinic_about.htm)

## Participate in aphasia research: the Aphasia Registry and Repository

- Registry: Researchers in the Aphasia Lab will have your name, phone number and address to contact you when new research studies become available.
- Repository: One-time testing sessions to help researchers understand more about aphasia. This testing will take about 2 hours.
- Research aphasia therapy: This is experimental therapy that has not yet been used in the community. Researchers have developed new and innovative therapies to help individuals with aphasia talk better.
- For more information about aphasia research, contact the University of Washington Aphasia Lab at (206) 685-2140
- <http://depts.washington.edu/sphsc/labsites/kendall/about.htm>

## Young Adult Stroke Survivors (YASS) and caregivers support groups

- Meets the 3rd Saturday of every month at Northwest Hospital Rehabilitation Center (1550 N. 115th Street, Seattle).
- Stroke group, 2-4pm: Individuals who have had a stroke and their family members meet for education, support and to build community.
- Caregiver group, 2:30-4:00pm: This caregiver group provides a forum for discussion about topics related to living with, and potentially caring for, someone who has had a stroke.
- Note: the July and August meetings are usually social gatherings held at alternative locations. See website for details.
- To find out more about this group, email Gerrit at [gerrit@exality.com](mailto:gerrit@exality.com) or call the University of Washington Aphasia Lab at (206) 685-2140.
- <http://seattleyass.weebly.com/>

## **Other local stroke support groups**

### **Virginia Mason Stroke Support Group (Seattle)**

- Meets 2<sup>nd</sup> Thursday of each month @11am, September-June, at Virginia Mason Medical Center Horizon House
- Call (206) 341-0199

### **Swedish Stroke Survivor Group (Seattle)**

- Meets last Tuesday of every month, 4-5pm at Swedish Cherry Hill
- Call (206) 320-3200, email StrokeProgram@Swedish.org

### **Stroke/Heart Support Group (Shoreline)**

- Second Tuesday of each month, 11am-12pm at the Shoreline Lake Forest Park Senior Center
- Call (206) 365-1536

### **Head Injury Support Group (Edmonds)**

- Meets 1st Tuesday of each month, 6:30-8:30pm at Edmonds Swedish Hospital
- Call (425) 776-7264

### **Providence Regional Medical Center Stroke Support Group (Everett)**

- Meets 2nd Friday of every month, in the medical office building next to the hospital
- Call Lisa Shumaker at (425) 404-6842

### **Whatcom Stroke Support Group (Bellingham)**

- Meets 2nd Thursday of every month, 2pm, St. Joseph Medical Center.
- Call (360) 788-6494

### **Eastside Stroke Support Group (Bellevue)**

- Meets 1st three Mondays of each month, 1-2:30, St. Andrews Lutheran Church
- Call (425) 746-8396

### **Living Well After Stroke (Kirkland)**

- Meets 1st Tuesday of every month, 2-3pm, De Young Pavilion
- Call (425) 899-3131

### **Snoqualmie Valley Stroke Support Group (Snoqualmie)**

- Meets 3rd Thursday of every month, 3:15-4, Snoqualmie Hospital Rehab Clinic
- Call (425) 831-2300 x204

### **Stroke Support Group (Silverdale)**

- Meets 3rd Thursday of each month, 1pm at CHI Franciscan-Harrison Silverdale
- Call (360) 744-8980, or email Kvanniel@harrisonmedical.org

### **Valley Medical Center Stroke Club (Renton)**

- Second Tuesday of every month, 6:30pm
- Call (425)656-5566, email StrokeCenter@valleymed.org

### **Tacoma Area Stroke Support Group (Tacoma)**

- Meets 3rd Thursday of every month, 6:30pm, TACID Building
- Call (253) 307-9961

## **Residential aphasia programs (United States)**

**Program for Intensive Residential Aphasia Treatment (PIRATE), Pittsburgh, PA Veterans Administration**

- <http://www.pittsburgh.va.gov/PIRATE/>

**Woodrow Wilson Residential Aphasia Program, Fishersville, VA**

- <http://wwrc.net/WWRAP.htm>

**The Aphasia Center, St. Petersburg, FL**

- <http://www.theaphasiacenter.com/intensive-aphasia-treatment-programs/>

## **Intensive aphasia programs (United States)**

**Yones Speech Therapy, St. Petersburg, FL**

- <http://www.yonestherapy.com/>

**Voices of Hope for Aphasia, St. Petersburg, FL**

- <http://www.vohaphasia.org/>

**Aphasia House, University of Central Florida, Orlando, FL**

- <https://www.cohpa.ucf.edu/clinic/aphasia/>

**Rehabilitation Institute of Chicago, Chicago, IL**

- <http://www.ric.org/conditions/stroke/clinically-advanced-rehabilitation/intensive-aphasia-program/>

**Northwestern University Intensive Aphasia Program, Evanston, IL**

- [http://www.communication.northwestern.edu/clinics/speech\\_language/aphasia\\_program.php](http://www.communication.northwestern.edu/clinics/speech_language/aphasia_program.php)

**University of Michigan Aphasia Program, Ann Arbor, MI**

- <http://mari.umich.edu/university-center-language-literacy/university-michigan-aphasia-program-umap>

**University of Montana Intensive Big Sky Aphasia Program (BSAP) - Comprehensive Aphasia Program, Missoula, MT**

- <http://coehs.umt.edu/departments/csd/DeWit%20RiteCare%20Speech,%20Language,%20and%20Hearing%20Clinic/big-sky-aphasia.php>

**Loyola University - Intensive Treatment for Aphasia Program (ITAP), Baltimore, MD**

- <http://www.loyola.edu/departments/clinical-centers/services/summer-programs/intensive-treatment-aphasia>

## **Organizations for people with aphasia (United States):**

### **National Aphasia Association:**

- [www.aphasia.org](http://www.aphasia.org)
- To purchase aphasia ID card: [www.aphasia.org/store](http://www.aphasia.org/store)

### **American Speech-Language-Hearing Association:**

- [www.asha.org/public/speech/disorders/Aphasia.htm](http://www.asha.org/public/speech/disorders/Aphasia.htm)

### **Aphasia Hope Foundation:**

- [www.aphasiahope.org](http://www.aphasiahope.org)

## **Resources from **aphasiacommunity****

<http://aphasia.community/resources/resources-for-aphasia-groups>

### **Australian-based website with a variety of resources for people with aphasia, including:**

- Manuals and tips for starting an aphasia group
- Writing aphasia-friendly documents
- Communicating and Conversation in Aphasia
- Research Articles:
- Educational videos
- Books about aphasia

# RESOURCES FOR FAMILIES DEALING WITH STROKE

## Organizations for stroke survivors

### **National Stroke Association**

- [www.stroke.org](http://www.stroke.org)  
1-800-STROKES (1-800-787-6537); [info@stroke.org](mailto:info@stroke.org)
- Several fact sheets related to recovery issues and an excellent handbook on stroke recovery issues for survivors and caregivers are available on their website. They can also help you find a support group and send you a free copy of StrokeSmart Magazine.

### **American Stroke Association**

- [www.strokeassociation.com](http://www.strokeassociation.com)  
1-888-4-STROKE (1-888-478-7653)
- On their website, learn more about stroke, healthy habits to control stroke risk factors, and stroke rehab and recovery. Read other people's stories and find out what's new in stroke research. Find out about stroke support groups in your area, talk with other stroke survivors and caregivers, and sign up to get Stroke Connection, a free magazine for survivors and caregivers

### **The National Center on Physical Activity and Disability**

- [www.nchpad.org](http://www.nchpad.org)
- Visit this website to access personalized tools and resources to help you meet your goals for physical activity—regardless of your disability.

### **Stroke Clubs International**

- (409) 762-1022
- Call for the name of a stroke club located in your area -- maintains list of over 800 stroke clubs throughout the United State

### **Rebuilding Together**

- [www.rebuildingtogether.org](http://www.rebuildingtogether.org)
- A national nonprofit group whose network of 200-plus affiliates furnishes free home modifications and repairs for low-income homeowners who are disabled and for seniors; many are stroke survivors

## **Free resources from the National Stroke Association**

### **HOPE Guide to Recovering from Stroke**

- <http://www.stroke.org/sites/default/files/resources/NSA-Hope-Guide.pdf>
- Recovery from stroke is a lifelong process. For many people recovery begins with formal rehabilitation. It is important for you and your family to know that no matter where you are in your recovery journey - there is always hope. Learn as much as you can about stroke and recovery, and the resources that are available. National Stroke Association has designed this publication to provide you with valuable information and help you on your road to recovery.

### **Fact Sheets**

- <http://www.stroke.org/stroke-resources/resource-library/fact-sheets>
- Includes the following topics: Driving, employment accommodations, bowel and bladder function, coping with emotions, dealing with pain, and many more.

### **Intimacy After Stroke:**

- <http://www.stroke.org.nz/resources/Sexuality-Booklet.pdf>
- This stroke booklet is informative and easy to understand. You can order free print copies by emailing [strokenz@stroke.org.nz](mailto:strokenz@stroke.org.nz).

## **Stroke survivor and caregiver magazines**

### **Stroke Smart Magazine**

- “Stroke Smart” is a FREE bi-monthly magazine published by the National Stroke Association. Contains articles for both stroke survivors and stroke caregivers.
- Subscribe at [www.stroke.org](http://www.stroke.org), or call 1-800-787-6537.

### **Stroke Connection Magazine**

- “Stroke Connection” is a FREE bi-monthly magazine published by the American Heart Association and the American Stroke Association. Also contains articles for both stroke survivors and stroke caregivers.
- Subscribe at [www.strokeassociation.org](http://www.strokeassociation.org), or call 1-888-478-7653.

### **Today's Caregiver Magazine**

- This bi-monthly magazine addressing the needs and concerns of caregivers, and is dedicated to those caring for loved ones with Alzheimer's, cancer, AIDS, and other threatening diseases.

## **Resources for caregivers**

The national organizations listed above under have information and support for stroke caregivers. In addition, caregivers may find resources from the following organizations helpful:

### **Family Caregiver Alliance**

- [www.caregiver.org](http://www.caregiver.org)  
(800) 445-8106
- FCA is a public voice for caregivers (primarily geared towards eldercare) and has developed a wide array of services and publications based on caregiver needs. FCA offers programs at local, state, and national levels. They provide information about common caregiving issues and strategies, how to deal with health and legal issues, caregiver FAQs and caregiver information in other languages. Additionally, their website offers an online caregiver support groups available through an email/list serve format.

### **National Alliance For Caregiving**

- [www.caregiving.org](http://www.caregiving.org)
- Dedicated to providing support to family caregivers and the professionals who help them and to increasing public awareness of issues facing family caregivers. They provide brochures on topics such as care for the caregiver, resources for caregivers, helping family caregivers through the process, and information on aging parents and palliative care.

### **Caregiver Action Network**

- [www.caregiveraction.com](http://www.caregiveraction.com)  
(202) 454-3970
- Formerly the National Family Caregivers Association. Maintains a peer support network that puts caregivers in touch with others in similar situations; offers a newsletter and other printed materials with information and resources. Educates supports, empowers and speaks up for the more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age.

### **The Well Spouse Foundation**

- [www.wellspouse.org](http://www.wellspouse.org)  
(800) 838-0879  
Email: [info@wellspouse.org](mailto:info@wellspouse.org)
- Well Spouse gives support to wives, husbands, and partners of the chronically ill and/or disabled. Well Spouse in-person support groups meet monthly and are peer-run. Here, members can share their thoughts and feelings openly with others facing similar circumstances in a supportive, non-judgmental environment. Provides support to spouses/partners of the ill or disabled through support groups, caregiver networks, and a bimonthly newsletter.

## **Caregiving.com**

- [www.caregiving.com](http://www.caregiving.com)  
(773) 343-6341
- Offers information about your needs as a caregiver, a caregiver blog, and online support groups. Focuses on caring for aging relatives.

## **Net of Care**

- [www.netofcare.org](http://www.netofcare.org)  
Email: findhelp@netofcare.org.
- Provides information for caregivers about what a caregiver is, how to cope as a caregiver, taking stock of your situation, and asking for help. Offers resources for internet chat rooms with other caregivers, and national caregivers organizations.  
Email: findhelp@netofcare.org.

## **Strength for Caring**

- [www.strengthforcaring.com](http://www.strengthforcaring.com)  
(866) 466-3458.
- In partnership with AARP. A one-stop meeting place for caregivers of a wide variety of health conditions. By entering your email address, you can sign up for a monthly newsletter, which includes highlights from all categories. Caregiver Manual offers very useful coping tips, and advice on issues such as balancing work and family, stress relief, food, fitness, wellness, comfort, and relaxation. Also, the newsletters' 'Our Experts' column offers practical, sensitive advice on common caregiver challenges.

## **Share the Care**

- [www.sharethecare.org](http://www.sharethecare.org)
- Sharethecaregiving, Inc. is a not-for-profit organization dedicated to educating the public about group caregiving as a proven option for meeting the needs of the seriously ill and their caregivers. Sharethecaregiving uses a widely adopted group caregiving model known as SHARE THE CARE. The SHARE THE CARE model provides a road map on how to form a caregiver team (comprising friends, relatives, neighbors, coworkers, and acquaintances) to provide individuals and families with the help they need to meet the daily challenges of caregiving.

## **Rosalynn Carter Institute**

- [www.rosalynncarter.org](http://www.rosalynncarter.org)
- Provides information on caregiving, including reading lists, video products, and other caregiver resources.



## **Creating a caregiving community**

### **Lotsa Helping Hands**

- [www.LotsaHelpingHands.com](http://www.LotsaHelpingHands.com)
- Secure website that allows friends, family, colleagues, and neighbors the opportunity to offer help to loved ones at crucial times. An easy-to-use private group calendar helps to coordinate tasks such as meals delivery, rides, and other tasks necessary to keep life running smoothly. Provides a space for status updates, message boards, and photo galleries.

### **Caring Bridge**

- [www.caringbridge.org](http://www.caringbridge.org)
- Secure, personalized website to help keep loved ones current and connected during difficult times. Each website includes a patient care journal to update family and friends, a guestbook for messages of love, a photo gallery, and free online support for using the service.

### **Care Pages**

- [www.CarePages.com](http://www.CarePages.com)
- Free, personal, private and secure service, which allows you to connect with family, friends, and others in your support circle, to share health updates or records of your emotions, worries, and successes. Registration is easy.

## **Caregiver CDs**

### **Emotional Renewal for Caregivers: Looking After Yourself While Helping a Loved One**

by Lynn Joseph, PhD

- This superb, 7-track, guided imagery CD targets caregiver stress in a wonderfully knowledgeable, compassionate and comprehensive way. Segments include an Intro with Advice, and imagery segments for: Boosting Self-Love, Planning a Smooth Day; Healing Stressful Feelings; Connecting with Your Future Self; Sleeping Soundly; and much more. Playing time: 72 min. Available at [www.healthjourneys.com](http://www.healthjourneys.com) or [www.amazon.com](http://www.amazon.com)

### **Caregiver Stress** by Belleruth Naparstek

- Imagery to remind the caregiver - whether family member or professional provider - of their own strength, goodness, tenacity and resourcefulness. Also designed to provide relaxation and balance; sustain motivation; reduce isolation; acknowledge the difficulties without sugar-coating them; help release any accrued resentment; and restore hope for the future. With affirmations. Playing time: 45 min. Available at [www.healthjourneys.com](http://www.healthjourneys.com) or [www.amazon.com](http://www.amazon.com)

## **Books**

Stronger After Stroke: Your Roadmap to Recovery by Peter G. Levine

Don't Leave Me This Way: Or When I Get Back on My Feet You'll Be Sorry by Julia Fox Garrison

Brain, Heal Thyself: A Caregiver's New Approach to Recovery from Stroke, Aneurysm, And Traumatic Brain Injuries by Madonna Siles, Lawrence J. Beuret

Lessons Learned: Stroke Recovery from a Caregiver's Prospective by Berenice Kleiman

After a Stroke: A Support Book for Patients, Caregivers, Families and Friends (The Family Health Series) by Geoffrey Md Donnan, Carol Burton

The Comfort of Home for Stroke: A Guide for Caregivers by Maria M. Meyer, Paula Derr

Passages in Caregiving: Turning Chaos into Confidence by Gail Sheehy

Caregiving: The Spiritual Journey of Love, Loss, and Renewal by Beth Witrogen McLeod

To Survive Caregiving: A Daughter's Experience, A Doctor's Advice on Finding Hope, Help and Health by Cheryl E. Woodson

## **How-to books for one-handed living**

Independent Living: Functioning With the Use of One Hand in a Two-Handed World by Patricia S. Burnett

Do It One-Handed: A Manual of Daily Living Skills for Stroke Rehabilitation by Susan Cohn