Who Are the Caregivers?

Jadene S. Ransdell

Each November, we take the time to recognize the individuals who work tirelessly to care for their loved ones. It’s important to create ongoing awareness of the contributions that family members who provide care for a loved one make—not only to their family but to our society at large.

From the NDSS publication, *Alzheimer’s Disease & Down Syndrome A Practical Guidebook for Caregivers © 2019*, “The word ‘caregiver’ encompasses a very diverse group: aging parents, siblings, extended family members, friends, volunteers, paid professional or lay staff, or other individuals in a committed relationship with the individual. Across all settings, caregiving is hard work. It can be a

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deeply loving, gratifying, and meaningful experience, while also being stressful, unpredictable, and mentally and physically depleting. Caregivers in our community have given a new meaning to the word, having to care for their aging children, many who will be diagnosed with dementia or Alzheimer’s at a young age. The very nature of Alzheimer’s disease, with its incremental and progressive decline, implies that caregiving takes stamina, and this process is a marathon, not a sprint. For that reason, it is critical that caregivers find ways to replenish themselves, physically, mentally, socially, emotionally and spiritually.”

Recently, family members who are part of a Facebook support group shared their thoughts about caregiving. They wrote about what they find to be the most difficult part of caregiving, things that siblings would like to have had their parents tell them, how they cope when they get overwhelmed, their biggest fear, and what it is that brings them joy. Not surprisingly, there was similarity with some of the comments. For example more than one caregiver wrote about the difficulty in accessing out-of-home care such as in a nursing home. Several stated that they have been denied services for their loved one because of age restrictions and disability.

Martha shared that although she knew what her parents wanted for her sister, she “had no idea how challenging it is to care for her, as it looked easy from my perspective. It’s hard to do on your own. My parents tagged teamed and it worked for them and my sib.”

Joann revealed, “watching my son regress, and not being the sweet guy he always was has been very hard for me. I have a true feeling of helplessness.” Pam imparted a similar sentiment saying, “the most difficult part of caregiving is watching my loved one lose so many abilities that took her so very, very long to learn.” Cindy wrote that, even though she has family who helps, “being there every minute of every day is so isolating!” Many families share these same feelings of loss, helplessness and isolation. It is one of the reasons that the Facebook group has been so well received—it provides a connection that the families may not otherwise have.

Cindy wrote about ways she deals with the overwhelm of caregiving. “...we take the dogs for a walk...we are both fans of 80s music so I turn it up loud and scream the lyrics and do housework!” That is certainly a creative way to deal with caregiving stress. Rebecca shared a blog that her daughter, Faith, has created to chronicle the travel they do together—a way of keeping Grace stimulated. Faith wrote in her blog titled, Traveling with a Special Needs Sister, “Unfortunately I am not a saint and struggle with the limits a handicapped sister brings. I am forced to walk slowly, taking about three times longer to do even the simplest activities with Grace had I done them myself. I watch other travelers jump on motorbikes to explore with autonomy and speed. I have to thank Grace for keeping me, in many ways, grounded. Surely, I would be as free as a bird off doing my own thing without her. But I don’t want to be like those who have no one counting on them, no one to support, or be accountable to. I’ve seen that freedom serve as a roadblock. It would be too easy for me to turn self-centered.” While not everyone will be able to travel like Rebecca, Grace and Faith, even short trips around the community, provide the sort of stimulation that keeps our loved ones brains working just a little bit longer. Several parents and siblings shared that when they get a glimpse of their loved one’s old personality, it makes them happy. The smiles and the belly laughs can brighten the worst days.

If you would like to connect with other caregivers, check out the Facebook group or consider joining one of our support groups. Some meet online and some meet face-to-face.

For more information about support groups, email us at ntgfAMILYadvocate@gmail.com.

The Facebook group can be found at (https://www.facebook.com/groups/DSALZ/)
10 TIPS FOR FAMILY CAREGIVERS

1. Seek support from other caregivers. You are not alone!
2. Take care of your own health so that you can be strong enough to take care of your loved one.
3. Accept offers of help and suggest specific things people can do to help you.
4. Learn how to communicate effectively with doctors.
5. Caregiving is hard work so take respite breaks often.
6. Make sure legal documents are in order.
7. Be open to new technologies that can help you care for your loved one.
8. Organize medical information so it’s up to date and easy to find.
9. Watch out for signs of depression and don’t delay getting professional help when you need it.
10. Give yourself credit for doing the best you can in one of the toughest jobs there is!

CaregiverAction.org
Your Everyday Resources

**Joshin:**
*Special Care. For Special Needs.*

Joshin is the first-of-its-kind disability care app that connects qualified and vetted caregivers (we call them, “Joymakers”) to families with special needs. Create and manage your schedule right from your smartphone. Joshin was created by siblings of Josh because they were aware of the difficulty families have finding caregivers for children and adults with special needs. Joshin is in limited areas at this time, but has plans for future expansion.

Call: 866.866.0345
Email: hello@joshin.com
On the Web: https://joshin.com/
On Facebook: https://facebook.com/joshincare/

**Caregiver Action Network (CAN)**

Caregiver Action Network is the nation’s leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. Although, this resource is not specific to families supporting individuals with intellectual disability and dementia, they have many resources that caregivers may find useful.

Caregiver Help Desk: 855.227.3640
Email: info@caregiveraction.org
On the Web: https://caregiveraction.org/
On Facebook: https://facebook.com/CaregiverActionNetwork/

**Adult Down Syndrome Center**

The Adult Down Syndrome Center is the country’s oldest clinic for adults with Down syndrome. Located in Park Ridge, Illinois, the Center is only able to see patients with Down syndrome who live in Illinois. However, they have an extensive online resource library. Brian Chicoine, MD, the Medical Director, recently announced major updates to their online library. The collections are focused on three audiences—people with Down syndrome, families and caregivers, and health care professionals. There are more than 250 resources in the library that were created by the Center and are free to access and use. There are some resources (such as medical journal articles) that require a fee to access.

Call: 847.318.2303
Email: laura.chicoine@advocatehealth.com
On the Web: https://adscresources.advocatehealth.com
On Facebook: https://facebook.com/adultdownsyndromecenter/
RAISE FAMILY CAREGIVER ADVISORY COUNCIL

In 2018, the RAISE Family Caregivers Act was signed into law. RAISE is an acronym for Recognize, Assist, Include, Support, and Engage. With that piece of legislation, the Secretary of Health and Human Services was directed to develop a national family caregiving strategy that will identify ways to recognize and support family caregivers. The strategy will include the promotion and adoption of person and family-centered care in healthcare and long-term service and support settings, as well as assessment and service planning that will involve care recipients and family caregivers. The strategy will also address respite options, financial security and workplace issues, information and education, referral, and care coordination.

As part of the Act, the RAISE Family Caregivers Advisory Council was established. The Advisory Council includes voting members who are family caregivers, and non-voting members from federal departments and agencies. According to Greg Link, from the Administration on Community Living, “Hundreds of family caregivers applied for one of the 15 non-federal positions. The make-up of the Advisory Council is broadly inclusive, as those selected reflect the breadth of caregiving experiences.”

Three of the non-federal members have a connection to people with intellectual/developmental disability (IDD). Joe Caldwell is director of the Community Living Policy Center at the Lurie Institute for Disability Policy, Brandeis University. He has more than 25 years of experience in the fields of aging, disability, and family caregiving as a researcher, policy expert, and family member. He is a proud step-father of a young adult and artist with Down syndrome. James S Cheely has served as the volunteer coordinator/coach of Special Olympics in his community (BARREN COUNTY FLAMES) for the past 18 years and has been involved locally, regionally, across the state, and nationally. He has also been involved with Advocates in Actions of the Arc of Kentucky, served as the president of the Arc of Kentucky for four years, and as the president of the Barren County Arc for two terms. He has a 31 year-old son with IDD. Nancy Murray, M.S., is the president of The Arc of Greater Pittsburgh at ACHIEVA. She has 40 years of experience in the disability field in the areas of public policy, advocacy, family support, supports coordination, health care, and state government. She has also served as a founder and coordinator of the Down Syndrome Center at Children’s Hospital (UPMC) of Pittsburgh, and the western area director of the Office of Developmental Programs in Pennsylvania.

The RAISE Family Caregiver Advisory Council wants to hear from you!

- Share what is the most specific challenge you face as a family caregiver.
- Share recommendations you may have that could address your concern.

Comments are due no later than Friday, February 7, 2020, 11:59 p.m. Eastern Standard Time,

Follow the link below to share your thoughts.
https://acl.gov/form/public-input-raise

The first meeting of the Advisory Council was held in Washington, DC in August, 2018; a livestream recording can be found on the web site. Their charge is to report to the Secretary models of effective family caregiving, support to family caregivers, and suggestions for improving coordination across federal government programs. Three subcommittees formed at that first meeting and identified their top two priorities.
Join self-advocates, families, and professionals as we explore topics meaningful to adults with Down syndrome.

Program Tracts:
- Advocacy
- Aging
- Alzheimer’s
- Caregiving
- Community & Residential
- Economic Self-Sufficiency
- Education
- Employment
- Health Promotion/Policy
- Research
- Sibling

Activities:
- DSWorks® Marketplace
- Exhibits
- Networking Event
- Dance Party

Where: Scottsdale/Phoenix, Arizona
When: May 7-9, 2020
For more information:
https://www.ndss.org/engage/ndss-syndrome-adult-summit-2020/

NDSS Focus on Aging and Caregiving

Our community is filled with pioneers. They are the parents who defied professionals and kept their babies with Down syndrome home, rather than place them in state-run institutions. They are the parents who worked to establish educational programs for their little ones with Down syndrome and other intellectual disabilities. In time, they added younger parents to their ranks and together they advocated for their children to go to school with their siblings and neighborhood children. Families created systems of supports to learn from each other as they raised their babies and watched them grow. Now, those support groups are often filled with young families who don’t understand the needs of parents whose children are growing into adults or are aging; parents may have lost touch with the families they knew when their son or daughter was younger. In some situations, the caregiving and support now comes from a sibling who has become responsible after a parent’s inability to be as involved or their death. So, we find families who have adults and are seeking, sometimes desperately, answers to new questions.

For families supporting adults with Down syndrome there is a critical need for:
- Advocacy
- Support
- Education
- Connection
- Research

As the home of the Down Syndrome Adult Summit, NDSS has recognized that families are hungry for current, accurate and practical information focused on the changing needs of adults with Down syndrome. Kandi Pickard recently said, “As the NDSS President and CEO, I am committed to expanding our support to adults with Down syndrome. We are excited to listen and learn from our self-advocates and their families as we develop our new Aging and Caregiving Initiative.”

Jadene S. Ransdell has been hired as the Senior Advisor of the Initiative and has already been communicating with family members to learn about their needs. She is working closely with other NDSS staff as they plan and develop the Initiative.

Contact Jadene at jransdell@ndss.org.
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**RAISE Family Caregiver Advisory Council**

Subcommittee 1: **Assist Caregivers in Optimizing Care and Support for their Loved Ones**
- **Priority #1:** Empowerment through resource identification and access
- **Priority #2:** Incentivize and support workforce development

Subcommittee 2: **Enable Caregivers to Provide Care While Maintaining their Health and Well-Being**
- **Priority #1:** Assessment to build a plan of care and support for family caregivers
- **Priority #2:** Increase and improve capacity to meet family caregiver needs:
  - Across the continuum of care/life
  - Short term and long term workforce development and financial consideration
  - Increase availability of resources and services
  - Uptake of evidence-based practices

Subcommittee 3: **Enhance Public Awareness, Education, and Engage Non-governmental Entities to Support Caregivers**
- **Priority #1:** Create the Value Proposition for family caregivers, work to identify gaps
- **Priority #2:** Identify and engage traditional and non-traditional partners

**Email:** RAISEAct@acl.hhs.gov

**On the Web:** http://www.acl.gov/RAISE

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**Submit Your Story**

We want to publish the stories of our readers, and we hope you will consider sharing your experiences related to caring for an individual with an intellectual or developmental disability who also has dementia.

We are now accepting stories for future issues of the *NTG Caregiver News*. Submit your story (between 500-1,000 words) in a Microsoft Word document file. Or, feel free to contact us with your story idea. We are always happy to work with you to write the story you would like to share. Write to us at ntgfamilyadvocate@gmail.com. Include “NTG Caregiver News Submission” in the subject line of your email. Below are the topics which will be the focus of upcoming newsletters. Although we are interested in receiving pieces on other subjects, additional consideration will be given to articles related to these topics.

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Quick Facts

On average, caregivers spend:

- **13 days each month** on tasks such as giving medication, shopping, food preparation, housekeeping, laundry, and transportation;

- **6 days per month** on dressing, grooming, feeding, walking, bathing, and assistance with toileting;

- **13 hours per month** researching care services or information on disease, coordinating physician visits or managing financial matters.

Gallup-Healthways, 2011, Gallup-Healthways, Well-Being Index. Family Caregiver Alliance: [https://caregiver.org](https://caregiver.org)

We’re on the web!

AADMD.org/NTG

For general information about the NTG: Seth Keller, Co-Chair: sethkeller@aol.com
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