Caring for Caregivers: Burnout and Resources for Caregivers in Rhode Island

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“I just need a break. I can’t leave the house because I’d feel nervous something would happen to my husband when I’m not there. Doctor, coming to see you is my break, and he’s even waiting for me in the waiting room. This is my life now, isn’t that sad?” You may not have met Sarah, the 77-year-old woman who cares for her husband with Alzheimer’s disease. But you know her. Sarah is the person we may all become, and the person we one day will surely count upon. Sarah is a caregiver.

According to the Rhode Island AARP, at least 148,000 Rhode Islanders are unpaid caregivers for loved ones, friends, or neighbors.1 As a state and as a country, we lean on our caregivers to provide care to those among us who are chronically ill, helping our sickest patients spend their last days, or years in the case of Alzheimer’s disease, at home in relative comfort. For all too many patients like Sarah, their often all-consuming role can overwhelm and lead to burnout. One study showed that as many as 75% of caregivers struggle with symptoms characteristic of anxiety and depression.2 This strain on mental health leaves lasting impacts on the physical health of caregivers. Among elderly caregivers, one study found that those experiencing significant emotional distress from their role had a 63% increased risk of four-year mortality compared to their non-caregiver counterparts.3

As a community, we as medical providers may at times feel stuck, wondering how we can offer support to our patients like Sarah, unsure of how to make the weight of their world a little bit lighter. As part of an Alpert Medical School master’s course in population and clinical medicine, we queried a group of 14 primary care providers [a mix of MDs and social workers in a primary care setting] in Rhode Island to obtain a sense of pre-existing knowledge of caregiver resources. On a scale of 1–5, with 1 being minimal familiarity, the healthcare providers rated their familiarity with existing resources for caregivers at a 1.5 out of 5. To broaden the awareness of caregiver resources, we delved into a selection of caregiver support programs as highlighted in the following sections. The appendices at the end of the section include additional links to information and application forms for discussed programs.

Care Breaks Program
Managed by the Diocese of Providence, this program, which is offered to people of all faiths, assists caregivers in scheduling and financing temporary caregiving alternatives, such as a home health visit, so caregivers can have a short break from their caregiver duties to attend to their own needs. Care Breaks is a cost-sharing program with graduated assistance based on income. Applicants must be Rhode Island residents caring for a disabled adult or child and not receiving other respite assistance from another state or federal program. The respite coordinator for the Rhode Island program can be contacted at 401-278-2511. The following links provide more information and applications.

Powerful Tools for Caregivers Program
A standardized, evidence-based curriculum available in Rhode Island, this program helps provide caregivers tools to communicate in challenging situations, make difficult caregiving decisions, and manage personal stress. The program is led by two certified peer leaders in weekly 2.5 hour group sessions over the course of six weeks. Participants receive The Caregiver Help Book, which is specifically designed for the course and contains guidance on, among other topics, issues related to medical aspects of caregiving, emotional and intellectual well-being, and legal and financial affairs.4 This program is free of charge and without any income requirements. Interested caregivers can contact the elder services outreach coordinator of the Diocese of Providence at 401-278-2528 and find any upcoming sessions here.

Alzheimer’s Association of Rhode Island
Dedicated toward assisting those suffering from Alzheimer’s disease and their families, the Rhode Island chapter of the Alzheimer’s Association offers a wealth of resources. Their 24-hour helpline at 1-800-227-2390 offers free caregiving tips, respite-care options, and information on resources available in patients’ communities. The Alzheimer’s Association hosts local support groups for Alzheimer’s disease patients, their caregivers and families. Additionally, the Association’s Early Stage Social Engagement program helps newly diagnosed patients navigate their new diagnosis, tools for maintaining a physically and mentally active life, all while giving their caregivers an opportunity for a break. Those interested can learn more about the Alzheimer’s Association’s resources here.
Rhode Island Caregiver Resource Manuals
To learn more about the resources already outlined and others, the Rhode Island Department of Elderly Affairs (DEA) arranged an easy to navigate “Pocket Manual for Seniors and Adults with Disabilities.” For a guide more concretely geared toward caregivers, the DEA’s “Guide for Caregivers” offers tips and resources organized by the age of the patient for whom a person is caring.

The challenges caregivers face are enduring and seemingly insurmountable, but they need not be borne alone. Armed with the knowledge of resources that are accessible to our patients and family members, the Rhode Island medical community should be equipped to offer aid to their patients like Sarah. In busy medical practice settings with competing priorities and time pressures, office support staff and allied professionals under physician direction may provide patients with information on available supports. Too often, our patients come to us feeling stuck, and we can and should empower them.

References
2. Liang, X, Guo, Q, Luo, J, Li, F, Ding, D, Zhao, Q, & Hong, Z. “Anxiety and depression symptoms among caregivers of care-recipients with subjective cognitive decline and cognitive impairment.” BMC Neurology, 2016, 16(1).

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Disclaimer
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Appendix A:
Additional High-Yield Resources for Caregiver Support
Start Here: RI Division of Elderly Affairs http://www.dea.ri.gov/
National Caregivers Library http://www.caregiverslibrary.org

Target Demographic for Caregivers
1. Children
   • Special Issues: Individualized Education Programs
   • Organizations: Parent Support Network of Rhode Island: www.psnri.org, Rhode Island Department of Health, Office of Special Health Care Needs: www.health.ri.gov/specialhealthcareneeds
2. Teenagers
   • Special Issues: Parent Advocacy Groups
   • Organizations: Rhode Island Parent Information Network: www.ripin.org, Rhode Island Department of Behavioral Healthcare, Developmental Disabilities and Hospitals: www.bhddh.ri.gov
3. Adults
   • Special Issues: Money Management, Children at Home
4. Older Adults
   • Special Issues: Independence, Assisted Living
   • Organizations: Diocese of Providence Respite Services: www.dioceseofprovvidence.org “Elder Services”, Rhode Island Division of Elder Affairs: www.dea.ri.gov
5. Veterans
   • Special Issues: Government vs Private Benefits
   • Organizations: Rhode Island Division of Veterans Affairs: www.vets.ri.gov, U.S. Department of Veterans Affairs: www.va.gov

Caregiver Tips
1. Self Care
   • Tips: Listen, Ask questions, Encourage Independence, Ask for Help, Get Support, Take Breaks, Be Kind to Yourself
   • Resources: National Caregivers Library: www.caregiverslibrary.org
2. Working
   • Tips: Temporary Caregiver Insurance, Family and Medical Leave Act, Rhode Island Parental and Family Medical Leave Act
   • Resources: American Association of Retired People: www.aarp.org/caregivingbook, Rhode Island Department of Labor & Training: www.dlt.ri.gov Click “Temporary Caregiver Insurance”
3. Financial Planning
   • Resources: Financial Planning Association of Rhode Island: www.fpari.org
4. Legal Documents
   • Tips: Advanced Directives, Living Wills, Power of Attorney, Medical Orders for Life-Sustaining Treatment, Guardianship
   • Resources: Rhode Island Department of Health: www.health.ri.gov. Click “Topics & Programs” and then “Advance Directives”, Rhode Island Bar Association: www.ribar.com
5. Emergency Plan
   • Tips: Basic Health Information, Medicine, Allergies, Advanced Directives, Legal Documents
   • Resources: Healthcentric Advisors: www.healthcentricadvisors.org/myccv