



Respite Overview
June 3, 2020

What we consider respite care - finding an alternate person/place to provide care/companionship for a loved one to provide 'space' for a caregiver to take a break (physical and / or emotional) - is often difficult for a caregiver to negotiate. It is not only understanding what one needs and is looking for – but it is actually locating available resources that is challenging. From end to end, it is not easy for a caregiver to quickly find what they need, when they need it. Services and information are disparate and disjointed; the task of searching is daunting, requiring time, patience, and PERSISTENCE.

- Finding what one needs or is looking for requires a conscious decision by the caregiver that help/assistance is needed.
- Beginning a search for resources entails access to and patience to track down information, make calls, and follow-through.
- The language of respite care, of seeking resources or help and assistance, is not common in our conversations – the words themselves can be a barrier to accessing services and resources.

In 2019, the National Alliance of Caregiving and AARP found only 12 percent of family caregivers used respite care services and we find similar levels of engagement in community resources overall in our research (11 percent of caregivers). In a sense, all resources and services (planning, home repair, companionship for the recipient) should be considered “respite,” if one does not know one needs them or that these services are available and accessible or does not access them.

Based on insights from National Alliance of Caregiving/AARP, we can safely say that most caregivers are experiencing some degree of stress/anxiety/depression. Our own data further supports the high incidence of stress, anxiety, and depression:

- 57% of caregivers report stress, anxiety, and / or depression (ARCHANGELS Caregiver Intensity Index, findings from May 2020)
- 92% of caregivers with a High CII report stress, anxiety, and / or depression (ARCHANGELS Caregiver Intensity Index, findings from May 2020)

Low caregiver utilization of community based or other respite tools and opportunities may be impacted by mental health status, awareness of resource options, and the wordstrings to ask for help in a way that feels comfortable to them.

What is out there?

The types of resources available to provide respite to caregivers is, as stated, disparate and disjointed. Although many sites provide an abundance of information and resources, the sheer volume can be overwhelming to cull and digest. There are MANY companies and organizations providing amazing services and resources – it is easy to see where a caregiver may struggle in knowing where to begin.

As we began sorting through the volumes of information, we made a couple of assumptions:

- Assume any service or tool can be respite to a caregiver



- This is the idea that a caregiver may never have known this existed, didn't know what to call it, or that this tool/service could alleviate some of their caregiver intensity.
- Only services/tools/resources for adults caring for adult caregivers were considered
- Sometimes, just having the information is better than not knowing about its existence at all
 - For example, transportation for the recipient may not be a concern now – however, having the information and knowing where to find it can alleviate future stress
- We found respite tools and services falling into seven categories
 - Emotional Support: support groups, virtual and otherwise
 - Home Delivery: pharmacy and caregiving supplies
 - Household Help: chores, minor home repairs
 - In Home Care: companionship, home makers, traditional paid caregivers, traditional respite services
 - Planning: legal, financial, health care decisions, end of life decisions
 - Resources: traditional sources of caregiving information and guidance
 - Tools (monitoring, coordinating care, communicating)
 - Transportation (reliable and trusted transport for care recipients to/from appointments)

Considerations for respite program development – in a way, it is about removing the barriers to seeking help/understanding what is available/accessing those services:

- Broaden the definition of respite – respite is more than coverage when a caregiver needs a break.
- Create a common vocabulary that caregivers and resources can use and understand.
- Make it comprehensive. Respite can be many things to a stressed/anxious/depressed caregiver.
- For traditional respite services, resources are difficult to find at best – and are **locally** based and staffed. Define the network of temporary care service providers and alternatives to make it easy for the caregiver to jump in and get started.
- Address the financial burden on caregivers. Caregivers contribute up to 30% of their income to provide care for their loved one. The reality is money for some is tight. Understanding where discounts on services, supplies, medications, medical equipment exist provides alleviation of some financial burden.
 - Understanding what government and state programs provide subsidies for care is needed as well.

Examples of Respite Services:

Emotional Support:

Caregiver action network

Website: caregiveraction.org

About: Connect family caregivers to resources, emotional support, and a Caregiver TOOLKIT.

Build online caregiver connections

Products: Toll-free Caregiver hotline (1-855-227-3640), free resources, live Chat

Pricing: Free

Service area: Nationally



Planning:

Have the Talk of a Lifetime

Website: talkofalifetime.org

About: The process of sitting down with loved ones to talk about their lives can be rich and satisfying. Learning about memorable events and people, places and favorite activities, values and lessons they have learned, can help bring us closer to those we care about most. Having the talk of a lifetime can make the difference of a lifetime. It can help reacquaint us with our loved ones and help us get to know them in a new and different way. Finding a way to start talking with a loved one may be the most difficult part; however we might find that once the conversation starts, it may be hard to stop.

Products: Downloadable discussion guides

Pricing: Free

Service area: Nationally

Resources:

Daily Caring

Website: dailycaring.com

Product: A site devoted to helping caregivers find practical information FAST -- they do the collating and culling. Information is sorted into sections where information is easy to find. Main sections are: COVID, Popular topics, daily care, caregiver stress, senior health, senior housing, finances and legal

Product: Online resources

Pricing: Free

Service area: Nationally

Home Delivery:

Carewell

Website: carewell.com

About: Online retailer for home care supplies - nutrition (ensure) to cleaning supplies to medical supplies (testing, wound care, etc), and DME -- like an all in one for homecare. (Even body wash). Free delivery on orders over \$39 -- Have a section called, "CAREGIVER FAVORITES"

Products: Online retail website

Pricing: No membership needed; Can set up recurring orders

Service area: Nationally

Household Help

Papa - grandkids on demand

Website: joinpapa.com

About: Papa connects College Students to Older Adults who need assistance with transportation, house chores, technology lessons, companionship, and other senior services. Students are called Papa Pals. Flexible booking (an hour to all day)

Product: on-demand, assistance service to help seniors stay independent while living securely and happily at home; Mobile app; Uber for seniors - transportation (to/from airport,



grocery shopping, doctor's appointments, errands; companionship, tech help, pet care, household - no personal care

Pricing: \$30/hour - Average visit = 3 hours

Basic membership - no monthly fee

* \$30 for first hour, then per minute

* Mileage: 10 mi included; pay \$0.50 per mi thereafter

Premium membership - \$30/month

Service area: Miami and Select Cities

In-Home Care

ARCH National Respite and Resource Center

Website: archrespice.org

About: National clearing house of respite services; includes National Respite Locator, National Respite Coalition

Products: National network of respite organizations; Other caregiver resources

Pricing: Free to \$25 Family Caregiver Annual Membership

Service area: Nationally

Tools

Lotsa Helping Hands

Website: lotsahelpinghands.com

About: Coordination of care across the caregiver team (friends, family, neighbors, doctor) mobile app - Features include Care Calendar, Announcements, Photo Gallery, and Well Wishes

Pricing: FREE

Service area: Nationally

Transportation

GOGO Grandparent

Website: gogograndparent.com

About: Access Lyft and Uber without a smartphone or internet - just call 1 (855) 464-6872

* Emergency contacts get updates throughout trip on their loved one's location!

* Voice commands on the toll free line"

Product: Transport concierge – available 24/7

Also have meal and grocery delivery

Pricing: \$0.27 / minute + Uber or Lyft fee

Service area: Nationally