

Respite Workbook for Families with Huntington's Disease

Being a care partner can be one of the most rewarding and challenging roles we face.

To continue to care for family members with HD who require support, we must remember to care for ourselves as well. This guide is meant to help care partners understand the meaning and importance of respite/short breaks, see real life examples, understand the possibilities and options that exist for respite, and create a successful plan that uses these breaks to enhance the lives of all family members.



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Getting Started

What is respite?

Respite is planned or emergency care giving a short break to care partners. It can be arranged for just an afternoon or for several days or weeks. Care can be provided in a variety of locations by family and friends or by professionals.



Why is it important?

Caring for someone with Huntington's disease can be very rewarding but can also be stressful and overwhelming at times. Everyone needs a break to do the things they need to do, like grocery shopping or going to your own doctor. It is equally important to make time to do the things you want to do such as hobbies or activities with friends.



For many HD families, it can be difficult to think about spending time apart from one another. As a care partner, entrusting the care of your loved one to someone else can cause feelings of anxiety, and for the person with HD, the very thought of going somewhere new, without their usual care partner, can be unsettling. They may refuse to participate in any discussion about the subject. However, recognizing the importance of short breaks for everyone can provide many positive benefits for all family members.

Care partners and their families who do not take regular and enough respite time to do the things they want and need to do, often experience greater stress, which can take a toll on their mental and physical health. Importantly, research shows that respite, which is personalized and purposely planned, benefits not only care partners, but all family members, including siblings or a spouse or partner.

Why you should have an emergency respite plan.

Emergencies happen. At some point, the care partner may get sick, have an accident, or be called away at the last moment. It's important to think through and know your respite options ahead of time. Emergency or crisis respite may be more difficult to find so familiarizing yourself with paid providers who might offer emergency respite or even registering in advance with such providers, is important. Alternatively, seek out local family members, friends, or neighbors who could be called in as the backup caregiver and discuss the plan with them.



Exploring Respite: What are my options?

Consider all of your options for support. Some people have friends or family in their lives that can step in as a backup caregiver. Community groups, religious organizations, or technology should also be considered. Look at the categories below to get a better idea of what might be available to you.

Relationship Based

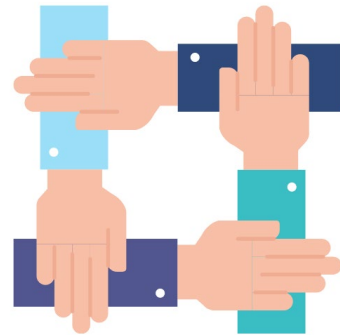
Family, friends, neighbors, co-workers, and other people might be able to help with something to enable the care partner to take a break. Example: A neighbor comes by for a visit while the care partner goes for a walk. A sibling or adult child may come stay at the house for a weekend so the care partner can take a quick vacation.

Technology

Using technology to help provide the support a person needs so the care partner can take a break. Example: Using video chat to check in with a caregiver who is not home or using a Google home device to remind someone to take medications.

Community Based

The places, activities and volunteers in the community. Example: A care partner may be able to take a break while his or her loved one participates in an activity at an Adult Enrichment Center or has a volunteer caregiver visit from the Center for Volunteer Caregiving.



Eligibility Specific

There are eligibility-based respite programs, as well as other kinds of support the care partner or care recipient may be eligible for based on age, income, diagnosis, or other criteria. Example: An adult is eligible for a companion program through their local Area Agency on Aging or a Medicaid Waiver.

Residential Facilities

Some long-term residential facilities, like nursing homes or assisted living facilities, have beds set aside for short-term respite for overnight, weekend or extended stays. To get started, visit local facilities and speak with the admission coordinator or marketing manager.

Making My Respite Care Plan

What Is a Respite Care Plan?

A respite care plan is notes and information to help prepare a substitute caregiver. A respite caregiver might be a family member, neighbor, or professional—but in all cases, a care plan can help them be well informed and give the best quality of care to your loved one.

Your respite care plan may be stored on a computer for easy updates, but it helps to have a printed, up-to-date packet that a caregiver can quickly access and find what they need.



What Should a Respite Care Plan Look Like?

Prepare your respite care plan with the following types of information:

1. Medical information
2. Personal routines
3. Interests and activity ideas
4. Emergency procedures

Your Respite Care Plan Template

Medical information

- List medications and dosage instructions.
- Keep the medications in their original bottles and in an easily accessible location.
- Write a summary of their symptoms of HD and any other diagnosis.
- Prepare a more comprehensive medical record in case the caregiver needs to refer to or share it in an emergency.
- List names and contact information for doctors.
- List all allergies to foods, medicines, and materials.
- Make special equipment (glasses, special utensils, shatterproof water bottle) accessible.



Personal Routines

- Write down your loved one's regular sleeping, waking, and mealtimes— Routines are vital to people with HD and sticking to their usual routine will be a necessity. Give your backup caregiver a detailed schedule.
- List some safe foods the person with HD enjoys and any special cups, bowls, or utensils that are used. Provide instructions about where the person with HD eats and any feeding instructions.
- List all of the activities they need help with, such as standing, walking, exercises, reading, personal care, and hygiene.



Emergency Procedures

- Create a list of emergency contacts with name, relation, phone number, backup phone number, and address for all people on the list.
- Give the information for the nearest hospitals and emergency rooms, including address, phone number, and open hours, if applicable.
 - Provide a copy of your evacuation plan in case of disasters

Resource Links

- Aging and Disability Resource Center (ADRC), part of the No Wrong Door System
<https://nwd.acl.gov/>
- ARCH Fact Sheets
<https://archrespice.org/productspublications/arch-fact-sheets>
- ARCH Fact Sheet on Respite for Family Caregivers of Persons with Dementia, including Alzheimer's Disease
https://archrespice.org/images/docs/Factsheets/FS_55-Alzheimers.pdf
- ARCH Fact Sheet on Respite for Veterans
https://archrespice.org/images/docs/Factsheets/fs_63-Respite_Caregivers_Veterans.pdf
- Eldercare Locator
<https://eldercare.acl.gov/>
- Services by State, Family Caregiver Alliance
<https://caregiver.org/family-care-navigator>
- Federal Funding and Support Opportunities for Respite
https://lifespanrespice.wildapricot.org/Federal_Funding_Guide
- Medicaid Waivers for Respite Support
- State-by-State Tables of Medicaid Waiver Information
https://archrespice.org/images/docs/Guides_Compilations/Medicaid_Waivers_for_Respite_2019.pdf
- Lifespan Respite Program Contacts
<https://www.archrespice.org/lifespan-programs>
- Medicare Hospice Benefit
<https://www.medicare.gov/Pubs/pdf/02154-Medicare-Hospice-Benefits.PDF>
- National Adult Day Services Association Organization – Choosing a Center
<http://www.nadsa.org/consumers/choosing-a-center/>
- National Respite Locator (NRLS)
<https://archrespice.org/respitelocator>
- State Respite Coalition Contacts
<https://archrespice.org/state-respice-coalitions>
- State Respite Registries
<https://lifespanrespice.wildapricot.org/StateRegistries/>