

Long-Term Care Planning Workbook

A guide for HD Families

Individuals with Huntington's Disease often need long term care in the later stages of the disease. This guide will help families understand when to think about long-term care, what care options are available, and how they are paid for.



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When to Start Planning for Long-Term Care

It's never too early to start planning for future care needs for the person with HD. Having an open and honest conversation early on about what the person with HD wants their future care to look like as well as evaluating how much care the family can personally provide is an important place to start. The individual with HD can share their preferences about care such as if they wish to remain at home or prefer to receive care in a facility setting. Setting up Advanced Directives and Power of Attorney forms early will help identify the wishes of the person with HD as well ensure a smooth transition of care decisions when the time comes. Often, the medical and physical needs of someone with late-stage HD requires more care than families can provide at home.



Signs that it may be time to start thinking about getting the person with HD more assistance or into a care setting include mobility issues, falls, un-kept or dirty living space, missing appointments, lack of food in the house or spoiled food that does not get thrown away, noticeable confusion when completing familiar tasks, late payments or stacks of unopened mail, unexplained weight loss, or forgetting or improperly taking their medication. All these things are indicators that the person with HD is not able to care for themselves like they once did.

Determining Levels of Care



When we talk about levels of care, we are referring to how much help the individual with HD needs. Doctors and healthcare professionals will examine the individual with HD and assess how many activities of daily living (ADLs) an individual can perform, their medical needs, cognitive impairments, and then make a recommendation about what type of care facility or how many hours of in-home care are needed.

If an individual with HD cannot be cared for safely at home, a primary care physician neurologist, or other medical professional may recommend transitioning the person to a care facility. They will be required to complete a government form called the FL2. This is a designation of the level of care needed for the person with HD. A link to this form can be found in the resources page of this workbook.

Long-Term Care Options

In-Home Care

Bringing a trained nursing assistant or nurse into the home can help when the symptoms of HD progress to a certain point. They can help with shopping for and preparing healthy meals that are easy to swallow, bathing and bathroom issues, and managing difficult behaviors.



Assisted Living Facility

Available to live in for long periods of time providing both meals and some assistance with healthcare and activities of daily living.

Adult or Family Care Home

A home with support and supervisory personnel that provides room and board, personal care and habilitation services in a family environment for not more than six resident persons with disabilities or illness.

Memory Care

Memory care is a form of residential long-term care that provides intensive, specialized care for people with memory issues. Many assisted living facilities, continuing care retirement communities and nursing homes have special memory care “neighborhoods” for dementia patients. There are also stand-alone memory care facilities. Memory care is often recommended for individuals with HD.



Skilled Nursing Facility

A residence providing skilled nursing and therapy staff. Their trained staff may provide medical care, occupational therapy, speech therapy, and physical therapy.

How to Pay for Long-Term Care

1. Medicare Coverage

Although Medicare does not cover the cost of senior living communities, it may include inpatient hospital stays, short-term skilled nursing and rehabilitation, hospice, and time-limited home health care.



Medicare is divided into four plans that cover a variety of services:

- **Part A:** Hospital insurance that covers inpatient hospital stays, care in a skilled nursing center, hospice care, and some home health care
- **Part B:** Medical insurance that covers certain doctors' services, outpatient care, medical supplies and preventive services.
- **Part C:** Medicare Advantage Plans are offered by a private company that contracts with Medicare to provide Part A and Part B benefits. Most Medicare Advantage Plans offer prescription drug coverage too.
- **Part D:** This plan adds prescription drug coverage to Original Medicare, some Medicare Cost Plans, some Medicare Private-Fee-for-Service Plans, and Medicare Medical Savings Account Plans.

2. Long Term Care Policy



If you have a long-term care policy, contact your policy provider to determine what your benefits provide and how to use them. Be aware that your policy might have an elimination period which is a period lasting 30, 60, or 90 days where you must cover the cost of any services you receive. Some policies specify that to satisfy an elimination period, you must receive paid care or pay for services during that time. Once your benefits begin most policies pay your costs up to a pre-set daily limit until the lifetime maximum is reached. Other policies pay a pre-set cash amount for each day that you meet the benefit trigger, whether you receive long-term care services on those days or not.

3. Converting a Life Insurance Policy

You may be able to convert an existing universal, whole, term or group life insurance policy to a pre-funded account to help pay for long-term care. This is a flexible option when it comes to financing senior living. Typically, many health conditions are accepted. The benefit may also be adjustable, so monthly payments could be altered to meet your changing healthcare needs.

Potential Benefits of a Life Insurance Policy Conversion:

Typically, life insurance policy conversions offer

- no waiting periods
- no premium payments
- no care limits
- no costs to apply



4. Medicaid

If you have Medicaid, there may be programs that provide in-home care. In North Carolina, there is a program called Personal Care Services (PCS), which can provide up to 80 hours a month of in-home care. This requires a doctor's order to start services. Also, the Community Alternatives Program for Disabled Adults (CAP-DA or CAP-Choice) can provide more care but has a significant waiting list in most counties. To apply for these programs, contact your Medicaid case worker.

Additionally, the individual with HD may qualify for Medicaid for Long Term Care. It is important to understand additional requirements for long-term care programs. For example, there are restrictions on income and resources. There are also rules on transferring assets and estate recovery. Your local Department of Social Services (DSS) will help determine if you are eligible for long-term care and which program fits your needs.

5. Veterans Aid and Attendance Benefit

Veterans and their surviving spouses may be eligible for a benefit called *Veterans Aid and Attendance*, which can help with a portion of assisted living and skilled nursing costs. If the person with HD is eligible for a Veteran's Administration pension and requires aid from another person, they may qualify for this benefit, in addition to their monthly pension.

They may qualify if they receive a VA pension *and* meet one of the following criteria:

- They need outside assistance to help perform daily activities. This includes bathing, dressing, or feeding.
- They stay in bed for most of the day due to illness.
- They are in a skilled-nursing home due to the loss of mental or physical abilities from a disability.
- The veteran's eyesight is limited, specifically if they have 5/200 vision or worse in both eyes, or concentric contraction of the visual field to 5 degrees or less — even with glasses or contact lenses

The Transition to Long-Term Care

Talking to an individual with HD about moving into a facility can be a difficult conversation. A clear understanding of the individual with HD's wishes makes the process easier for everyone involved. Deploying empathy will also go a long way to make the conversation and the transition easier. Once the individual with HD moves to a care facility there is often a period of adjustment for both the person with HD and the family. Conflict with roommates, issues with the food, adjustment to facility routines, and lost items are typical in the first weeks. Keep in mind that these are common issues and will often work themselves out over time as the person with HD adjusts and gets to know the facility, roommates, and staff.



As a family member, you can step into the role of advocate. Get to know the staff, most importantly the Certified Nursing Assistants (CNA). CNA's will spend the most time with the person with HD and chances are they will be unfamiliar with the disease. Educate them on the disease so they can have insight into how to work with the person with HD. Family members, HD Reach clinicians, and social workers from your HD clinic, can all provide education and resources to the facility staff as well.

Resources

- Listing of Skilled Nursing facilities by County (North Carolina)
<https://info.ncdhhs.gov/dhsr/facilities/search.asp>
- Listing of Adult Care home and Family Care Home by County (North Carolina)
<https://info.ncdhhs.gov/dhsr/reports.htm>
- FL2 Form North Carolina
<https://medicaid.ncdhhs.gov/providers/forms/adult-care-home-and-personal-care-services-forms>
- <https://www.hdreach.org/living-well/housing-advance-planning-financial-decisions/finding-long-term-care/>
- <https://www.hdreach.org/treating-hd/resource-guides/long-term-care-hd-unit.html>
- Facility Tip Sheet; CNA's First Shift by Jimmy Pollard
<https://www.hdreach.org/living-well/resources.html>
- Tips for interviewing long term care facilities
<https://www.hdreach.org/living-well/resources.html>