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Home > Life > How to Prepare for the End of Life: A Guide for People With Bleeding Disorders



# How to Prepare for the End of Life: A Guide for People With Bleeding Disorders

## Use this guide to decide what's important to you and what care you need.

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Adults & Aging

The end of life is something everyone faces but few people want to discuss. Advances in medicine have extended the lives of many people with inheritable blood and bleeding disorders.

"We frequently now have patients with bleeding disorders living otherwise normal life expectancies, so we're not as well prepared for what end-of-life care will look like for them," says David Hedrick, M.D., an adult hematologist-oncologist at the Indiana Hemophilia & Thrombosis Center. He urges people to prepare for end-of-life care with their families and doctors as early as possible.

If you don't know where to start, your **hemophilia treatment center (HTC)** can help. "HTC social workers are trained in medical decision-making processes, including end-of-life care," says Bryn Dunham, LCSW, a social worker at the Hemophilia and Thrombosis Center at the University of Colorado Anschutz Medical Campus.

It's good to take a holistic approach that goes beyond medical planning. "Sometimes that includes planning funeral services, making amends with family members, or dividing certain possessions," Dunham says. "It's really about taking control of the dying process rather than the dying process taking control over you or the caregiver."

Breaking down end-of-life care planning can also help. Here's how.

## Create a Plan for Medical Decision-Making

Get the proper legal documents in place to help doctors and caregivers manage your care as you wish. These include a durable medical power of attorney and a living will.

With a durable medical power of attorney, also called a health care proxy, you appoint someone to make medical decisions for you if you can't make them yourself.

A living will, which is different from an inheritance will, outlines the medical treatments you would and wouldn't want at the end of your life. Some hospitals and HTCs have their own living will documents you can fill out and keep on file.

## Decide Between Palliative and Hospice Care

Palliative care manages symptoms related to a serious illness, such as cancer or heart failure, at any stage, not just the end of someone's life. You can receive palliative care (also called comfort care) along with treatment to cure your illness, such as chemotherapy for cancer.

Hospice care is for people who are dying. It's also a Medicare Part A and medical insurance benefit administered by a hospice care provider.

To enroll in hospice care, a health care provider must certify that you have a terminal illness and have six months or less to live. Also, you must agree to stop any curative treatment for your terminal illness, though you can still receive palliative care to manage physical and mental health symptoms or other chronic health conditions.

A hospice physician will manage your primary care. Depending on what your insurance allows, the physician can coordinate palliative care, including the use of prophylaxis, with your HTC team, Hedrick says.

## Find Out What Your Insurance Covers

Medicare policies usually provide good coverage for palliative and hospice care for people with bleeding disorders, Dunham says. "But if you have a medigap policy or private insurance, you want to call them to find out about benefits."

People with blood and bleeding disorders can run into problems that other people on hospice care don't face. In general, treatments such as blood transfusions are not covered or allowed under hospice care because they are seen as curative or life-extending, Hedrick explains. So, you need to find out ahead of time what palliative care rules your insurance or hospice provider has for bleeding disorders.

"Occasionally, we have had issues with clotting factor being covered," Hedrick says.

Your local HTC can advocate on your behalf and help explain the special circumstances for people with bleeding disorders. "Our HTC will work with a hospice physician to ensure that there's access to factor products and anything else that would keep the person comfortable and would help them maintain their quality of life," Dunham says.

## Research Support Services

Know the resources and support services that are available in your community. Your HTC is the best place to start. You can also contact your local **Area Agency on Aging**; these are public or private nonprofit, state-designated groups that provide resources and support services for older people and their caregivers.

## Review Your Care Options

Different hospice providers offer different services. Before you choose one, compare them. Focus on what's important to you and your loved ones and which services can add to your quality of life.

Some hospice programs offer special services such as art therapy and music therapy. Some have respite care, where trained volunteers sit with the person for a few hours so caregivers can take a break.

HTC social workers often know which local hospice agencies or nursing facilities can handle the complexities of people with bleeding disorders. "Some of it is dictated by insurance," Hedrick says. "But we build relationships with the facilities and organizations in the area to know the best places for bleeding disorders patients."

The Steps for Living website has a wealth of information for adults, including topics on **aging and bleeding disorders**.

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