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Subject: A Person-Centered Approach to Advanced Illness

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A Person-Centered Approach to Advanced Illness

By Edwin L. Walker, Acting Assistant Secretary for Aging and Acting Administrator, Administration for Community Living

At ACL, we believe that every person has the right to make choices and to control their own decisions. This right is independent of age or disability.

This right also is not diminished by illness. People who have advanced illnesses should have control over their care and services.

For a person with advanced illness to be in control, several things must happen. First, people need to be informed and have the opportunity to express their preferences. Second, service providers must respect those preferences and place individual choices at the center of treatment decisions -- whether the decision involves avoiding unwanted treatments or providing services that an individual does want. Service providers should honor the individual's choices, help manage their symptoms, and provide needed emotional and spiritual supports to them and their families.

This is what stakeholders have been telling us at the Administration for Community Living.

As part of our role as an advocate for the rights of older adults and people of all ages with disabilities, at all stages of life, ACL is exploring ways to support an individual's choice and control during advanced illness. One of our goals is to help ensure that when a person is very ill, they and their families do not face discrimination based on assumptions about age or disability. We also are promoting the voice of the individuals with advanced illness within policy conversations.

We are developing a set of principles, reflecting areas of potential consensus among various aging and disability communities about care during advanced illness. We will use these principles to inform future advocacy related to advanced illness among older adults and individuals with disabilities.

We invite you to help us continue this sometimes difficult, but critically important, discussion by providing your thoughts to AdvancedIllness@acl.hhs.gov.

We know there are a wide variety of deeply held perspectives on these issues and

we are committed to better understanding them and we will consider all of them carefully.

Please [read the full blog](#) for more detail on this issue and ACL's work in this area.

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