



End of Life Planning

Resources and Guidance

Education

Before: Preparing for the End of Life

Advance Directives and Advance Care Planning for People with Intellectual and Physical Disabilities

<http://aspe.hhs.gov/daltcp/reports/2007/adacp.pdf>

This is a report prepared for the Office of Disability that describes the current status of advance care planning and identifies where gaps exist. The aim of the report was to better assure that the needs and issues of people with disabilities are considered when new policies are designed to promote effective advance care planning.

Caring at the End of Life

http://aaidd.org/content_170.cfm?navID=31

This is a Position Statement prepared by AAIDD – the American Association on Intellectual and Developmental Disabilities. AAIDD is the oldest and largest organization of professionals and citizens concerned about intellectual and developmental disabilities. Their position statements state the Association's position on important issues related to intellectual and developmental disabilities practice, policy, or research.

Easyhealth

<http://www.easyhealth.org.uk/listing/dying-%28leaflets%29>

This website contains various pamphlets and booklets on the topic of dying. All the information uses easy words with pictures.

End of Life Documents - legal documents to convey end of life wishes and health care decision makers

Five Wishes

<http://www.agingwithdignity.org/>

http://www.agingwithdignity.org/catalog/nonprintpdf/Five_Wishes_Final.pdf

The *Five Wishes* is an easy to use legal document written in everyday language that lets adults of all ages plan how they want to be cared for in case they become seriously ill. It is America's most popular living will. *Five Wishes* helps you express how you want to be treated if you are seriously ill and unable to speak for yourself. It is unique among all other living wills and health agent forms because it speaks to all a person's needs: medical, personal, emotional and spiritual. *Five Wishes* also helps structure discussions with your family and physician.

Pennsylvania Advance Directives for Health Care Declaration or Living Wills

<http://www.portal.state.pa.us/portal/server.pt?open=514&objID=616602&mode=2>

This is the advance directive document used in Pennsylvania. It is a written document that you may use, under certain circumstances, to tell others what care you would like to receive or not receive should you become unable to express your wishes at some time in the future.

Financial Considerations

http://www.dpw.state.pa.us/foradults/burialandcremationservicespayment/S_001023

This site provides information on burial and cremation services payment from the Pennsylvania Department of Public Welfare

Hospice Services

The National Hospice and Palliative Care Organization

<http://www.nhpc.org/i4a/pages/index.cfm?pageid=4648>

HELPGUIDE

http://www.helpguide.org/elder/hospice_care.htm#services

Caring.com – list of hospices in Pennsylvania by city and county

<http://www.caring.com/local/hospices-in-pennsylvania>

Last Passages

<http://www.albany.edu/aging/lastpassages/index.html>

Last Passages is a joint project of the Volunteers of America, the University at Albany, NYSARC, Inc. and Marist College. The purpose of the Last Passages project is to share information and promising practices to enhance end-of-life care for people with developmental disabilities.

Let's Talk About Death

<http://www.easyhealth.org.uk/sites/default/files/lets%20talk%20about%20death.pdf>

This booklet was created by Down's Syndrome Scotland. This organization works to improve the quality of life for everyone in Scotland with Down's syndrome and their families.

Preferred Priorities for Care (Easy Read)

http://www.endoflifecare.nhs.uk/search-resources/resources_search/publications/imported-publications/preferred-priorities-for-care-document-easy-read-version.aspx

This is a document from the United Kingdom. It is an easy read version of the Preferred Priorities for Care (PPC) document and is designed to help people with learning disabilities prepare for the future. It gives people an opportunity to think about, talk about and write down their preferences and priorities for care at the end of life.

The Conversation Project

<http://theconversationproject.org/starter-kit/intro/>

This project began in 2010 and is dedicated to helping people talk about their wishes for end-of-life care. This group met because too many people are dying in a way they wouldn't choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain. They want to transform our culture so we shift from not talking about dying to talking about it. They feel it is time to share the way we want to live at the end of our lives. And it's time to communicate about the kind of care we want and don't want for ourselves. They believe that the place for this to begin is at the kitchen table—not in the intensive care unit—with the people they love, before it's too late.

To aid in this process they have created a "starter kit" to help people get their thoughts together and then have the conversation. This isn't about filling out Advance Directives or other medical forms. It's about talking to your loved ones about what you or they want for end-of-life care.

Thinking Ahead

http://coalitionccc.org/_pdf/Thinking_Ahead_English_web.pdf
<http://coalitionccc.org/thinking-ahead.php>

Thinking Ahead: My Life at the End is a booklet that contains words, symbols and pictures that facilitate discussion with and decision-making by persons with developmental disabilities regarding their values, goals and treatment preferences at the end of life. Thinking Ahead was

made possible through a Wellness grant awarded to Alta California Regional Center by the California Department of Developmental Services and reflects collaboration among Alta California, Golden Gate and Eastern Los Angeles Regional Centers, Board Resource Center and the Coalition for Compassionate Care of California.

When I Die

http://www.easyhealth.org.uk/sites/default/files/when_i_die_1_0.pdf

http://www.easyhealth.org.uk/sites/default/files/when_i_die_2_0.pdf

This is a guide for people with intellectual disability created in the United Kingdom. It is a booklet template so that people can document their end of life wishes.