

Participant Companion Guide

Module 8: *Behavioral Health Issues and Advance Care Planning*

Resources related to
Advance Care Planning, Guardianship, Conservatorship, Involuntary
Commitment



BUILDING PARTNERSHIPS FOR
OLDER ADULT BEHAVIORAL HEALTH

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I. End-of-Life Planning Resources

General

Title: The Aging and Disability Resource Connection of Oregon (ADRC)

Audience: Consumers and Professionals

Topic: Information, assistance, and referral to community resources and supports

Description: Provides people of all ages, incomes and disabilities with information on the full range of long-term support options available in their communities.

Link: <https://www.adrcoforegon.org/consite/index.php>

Resource: Aging and Disability Resource Center (ADRC) of Oregon

Title: Advance Care Planning

Audience: Consumers

Topic: Advance care planning

Description: Provides information about advance care planning. This includes decisions that come up near death, how to get started on your advance care planning, options for how to make your wishes known, selecting a healthcare proxy, how to make your advance care planning decisions official, and what to do after you have made your decisions.

Link: <https://www.nia.nih.gov/health/publication/advance-care-planning>

Resource: National Institute on Aging (NIA)

Title: End of Life: Helping with Comfort and Care

Audience: Consumers

Topic: End of life decision making

Description: This is one part of a larger piece on end-of-life issues. This section provides information about planning for and making decisions about end-of-life care, including advance directives.

Link: <https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/planning-end-life-care-decisions>

Resource: NIA

Title: Advance Care Planning

Audience: Consumers

Topic: Advance care planning

Description: Provides links on how to communicate your end-of-life wishes to loved ones, healthcare providers, and others. Also provides helpful PDF resources and handouts for talking about end-of-life decision making.

Link: <http://www.caringinfo.org/i4a/pages/index.cfm?pageID=3527>

Resource: National Hospice and Palliative Care Organization

Title: A Better Way of Dying

Audience: Consumers

Topic: End-of-life planning

Description: This book describes a five-step Compassion Protocol and offers a framework for leaving caretakers instructions about a person's wishes for their last days.

Link: Can be purchased at local and web-based bookstores

Reference: Penguin Books

Title: Dr. Atul Gawande: "Hope is Not a Plan" When Doctors, Patients Talk Death

Audience: Consumers

Topic: End-of-life planning

Description: Interview with Dr. Atul Gawande, a surgeon at Boston's Brigham and Women's Hospital and the Dana-Farber Cancer Institute, discusses some of the harmful cultural ideologies and anxieties surrounding death which can inhibit individuals and patients from living the remainder of their life with dignity.

Link: <http://www.pbs.org/wgbh/pages/frontline/health-science-technology/being-mortal/dr-atul-gawande-hope-is-not-a-plan-when-doctors-patients-talk-death/>

Reference: Frontline

Title: Being Mortal: Medicine and What Matters in the End

Audience: Consumers and Professionals

Topic: End-of-life care, end-of-life decision making

Description: Link to a book by Dr. Atul Gawande, a surgeon at Boston's Brigham and Women's Hospital and the Dana-Farber Cancer Institute, who discusses some of the harmful cultural ideologies and anxieties surrounding death which can inhibit individuals and patients from living the remainder of their life with dignity.

Link: <http://atulgawande.com/book/being-mortal/>

Reference: Atul Gawande

Title: How to Die in Oregon

Audience: Consumers

Topic: End-of-planning, Death with Dignity Act, physician-assisted suicide

Description: Home site of the film “How to Die in Oregon” which takes a look at the Death with Dignity Act in Oregon where individuals who are terminally ill may request physician-assisted suicide. This site provides information about the movie, about the director, the trailer, news, reviews, and links to watch the film.

Link: <http://www.howtodieinoregon.com/>

Reference: How to Die in Oregon

Title: Death with Dignity National Center – In Oregon

Audience: Consumers

Topic: Death with Dignity Act, physician-assisted suicide

Description: Provides an overview and history of Oregon’s Death with Dignity Act including the legal and political timeline, Oregon annual reports, and other resources related to this act.

Link: <http://www.deathwithdignity.org/in-oregon>

Reference: Death with Dignity National Center

Alzheimer’s Disease

Title: I have Alzheimer’s Disease

Audience: Consumers

Topic: End-of-life planning

Description: Provides information about end-of-life planning for individuals with Alzheimer’s disease.

Link: <http://www.alz.org/i-have-alz/plan-for-your-future.asp>

Reference: Alzheimer’s Association

END-OF-LIFE PLANNING DOCUMENTS

Title: Legal Help: Develop Necessary Documents

Audience: Consumers

Topic: Legal help, end-of-life planning

Description: Provides information about the legal documents needed for end-of-life planning including financial power of attorney, representative payee, trust, advance directive for health care decisions, and physician orders for life-sustaining treatment (POLST).

Link: <https://adrcforegon.org/consite/plan-legal-and-care-planning-develop-documents.php>

Reference: ADRC of Oregon

Title: Oregon POLST Registry (OPR)

Audience: Professionals

Topic: POLST

Description: OPR is a secure electronic database. The Registry allows health care professionals treating a patient access to their POLST orders if the paper POLST form cannot be found.

Link: <http://www.orpolstregistry.org/>

Reference: Oregon POLST Registry

Title: POLST: Doing it Better

Audience: Professionals

Topic: POLST

Description: The Center for Ethics in Health Care at OHSU and the Oregon POLST Task Force Education Committee developed this educational video for health care professionals. This video reviews who the intended audience is for POLST and some common misconceptions about POLST.

Link: <http://www.or.polst.org/news/2015/9/8/new-polst-educational-video-released>

Reference: POLST Oregon

Title: Patients & Families Understanding POLST

Audience: Consumers

Topic: POLST

Description: Provides information videos, patient and family resources and information about POLST forms, FAQs, and the POLST process, and professional resources including ordering and printing POLST, the POLST process, and FAQs.

Link: <http://www.or.polst.org/>

Reference: POLST Oregon

Title: Elder Rights and Abuse Prevention

Audience: Consumers and Professionals

Topic: Elder rights, elder abuse, abuse prevention, guardianship, conservatorship, powers of attorney, representative payees/VA fiduciaries, advance directives, appointed health care representative, civil commitment

Description: Provides a variety of tools, documents, and forms for older adults in their end-of-life decision-making and fiduciary planning including materials related to guardianship, conservatorship, powers of attorney, representative payees/VA fiduciaries, advance directives, appoint health care representative, and civil commitment. Provides information about and tools for adult abuse prevention.

Link: <http://www.oregon.gov/dhs/spwpd/pages/sua/elder-rights.aspx>

Reference: Oregon Department of Human Services – Aging and People with Disabilities (APD)

Advance Directive

Title: Oregon Advance Directive: Planning for Important Health Care Decisions

Audience: Consumers

Topic: End-of-life planning, advance directive

Description: Legal document with specific instructions about preferences for end-of-life care.

Link: http://www.aarp.org/content/dam/aarp/relationships/caregiving/2011_01/ad/Oregon.pdf

Reference: AARP

Declaration of Mental Health Treatment

Title: Mental Health Law in Oregon

Audience: Consumers and Professionals

Topic: Mental health treatment, law

Description: Provides information about the rights and protections that individuals with mental health conditions have under Oregon law

Link: <http://droregon.org/wp-content/uploads/Mental-Health-Law-in-Oregon-Fourth-Edition.pdf>

Reference: Disability Rights Oregon

Title: A Guide to Oregon’s Declaration for Mental Health Treatment

Audience: Consumers

Topic: Mental health

Description: Provides information about Oregon’s Declaration for Mental Health Treatment including an FAQ, instructions, as well as the document itself.

Link: <http://www.oregon.gov/oha/amh/forms/declaration.pdf>

Reference: Oregon Health Authority (OHA)

CAPACITY

Title: At-Risk Driver Program

Audience: Consumers and Professionals

Topic: Capacity

Description: Provides information about Oregon DMV’s At-Risk Driver Program

Link: <http://www.oregon.gov/odot/dmv/pages/driverid/medical.aspx>

Reference: Oregon Department of Motor Vehicles (DMV)

Title: Aid to Capacity Evaluation
Audience: Professionals
Topic: Capacity
Description: This is a tool to be used to evaluate the capacity of an individual.
Link: <http://www.aafp.org/afp/2001/0715/afp20010715p299-f2.pdf>
Reference: American Academy of Family Physicians

Title: Performing capacity evaluations: What's expected from your consult
Audience: Professionals
Topic: Capacity
Description: Discusses competency and capacity differences, capacity evaluation components, tools physicians use to determine capacity. Can be printed in PDF format.
Link: http://www.currentpsychiatry.com/view-pdf.html?file=uploads/media/041_0114CP_Sorrentino_FINAL
Reference: Current Psychiatry

Title: ADRC Dementia Care Training Module 8: Decision Support for Advanced Care and End-of-Life Planning
Audience: Consumers and Professionals
Topic: Capacity, legal planning, financial planning, advance directives, health care advance planning, elder abuse and neglect, guardianship, conservatorship, and end-of-life care
Description: This module addresses financial, legal, health and end-of-life issues associated with advance care planning, and the importance of knowing about available end-of-life supports and services.
Link: <http://www.oregon.gov/dhs/spwpd/sua/docs/Dementia%20Training%20Module%208.pdf>
Reference: ADRC of Oregon

ADVANCE DIRECTIVE

Title: Advance Directive
Audience: Consumers
Topic: Advance directive
Description: Provides information about advance directives including an advance directive planning kit and advance directive FAQs.
Link: <https://oregonhealthdecisions.org/index.php>
Reference: Oregon Health Decisions

Title: Completion of Advance Directives Among U.S. Consumers
Audience: Professionals
Topic: Advance directive
Description: Characterizes adults who did and did not have an advance directive and examines factors associated with their completion.
Link: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4540332/>
Reference: American Journal of Preventive Medicine

Title: Federal Law on Advance Directives
Audience: Professionals
Topic: Advance directive law
Description: : Provides information about the rights of health care users to stipulate in advance how they would like to be treated by health care providers when they are incapacitated.
Link: <http://www.nrc-pad.org/images/stories/PDFs/fedaddirectives2a.pdf>
Reference: National Resource Center on Psychiatric Advance Directives

Title: Psychiatric Advance Directives (PAD)
Audience: Consumers and Professionals
Topic: An overview of PAD, NAMI's position on PAD, and ways to take action
Description: Provides links to understanding the issue, NAMI's support of PAD, and how to advocate for PAD.
Link: https://www2.nami.org/Template.cfm?Section=Issue_Spotlights&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID=5&ContentID=8217
Reference: National Alliance on Mental Illness (NAMI)

Title: National Resource Center on Psychiatric Advance Directives: Oregon Q and A
Audience: Consumers and Professionals
Topic: Psychiatric advance directives
Description: Provides information about Oregon psychiatric advance directives, relatively new legal instruments that may be used to document a competent person's specific instructions or preferences regarding future mental health treatment.
Link: <http://www.nrc-pad.org/states/oregon-faq>
Reference: National Resource Center on Psychiatric Advance Directives

GUARDIANSHIP AND CONSERVATORSHIP

Title: Guardianships & Oregon Public Guardian and Conservator
Audience: Consumers and Professionals
Topic: Guardianship

Description: Provides an overview of guardianship, how to establish guardianship, and public guardianship in Oregon.

Link:

https://www.oregonlegislature.gov/citizen_engagement/Reports/BB2014GuardianshipsAndPublicGuardian.pdf

Reference: State of Oregon

INVOLUNTARY (CIVIL) COMMITMENT

Title: Civil Commitment

Audience: Consumers and Professionals

Topic: Civil commitment

Description: Provides information about what civil commitment is and is not, when it is appropriate, and a link to general standards and procedures relating to involuntary commitment.

Link: <http://www.oregon.gov/oha/amh/Pages/civil-commitment.aspx>

Reference: OHA

REPRESENTATIVE PAYEE

Title: Representative Rights Facts: Disability Rights Oregon

Audience: Consumers

Topic: Representative payee

Description: Answers FAQs about representative payee's roles and responsibilities, how to address disagreements with a payee, and how to change a payee.

Link: <http://droregon.org/wp-content/uploads/FAQ-Rep-Payees.pdf>

Reference: Disability Rights Oregon

Title: A Guide for Representative Payees

Audience: Consumers and Professionals

Topic: Representative payee guidelines

Description: This booklet provides basic information on how to be a representative payee.

Link: <http://www.ssa.gov/pubs/EN-05-10076.pdf>

Reference: Social Security Administration

HEALTH CARE REPRESENTATIVE

Title: Role of health care representative is increasingly important

Audience: Consumers and Professionals

Topic: Health care representative, advance directive, POLST

Description: Provides information about the health care representative's roll, family discussion issues and topics, advance directive and POLST.

Link: http://www.osbar.org/docs/sections/elder/newsletters/elder_sum05.pdf

Reference: Elder Law Newsletter

CAREGIVERS AND CAREGIVING

Title: Caregiving Resource Center

Audience: Consumers and Professionals

Topic: End-of-life planning

Description: Provides families with information and resources on how to plan and organize for end-of-life decisions including benefits/insurance, legal/financial, senior housing, and grief/loss.

Link: <http://www.aarp.org/home-family/caregiving/end-of-life/>

Reference: American Association of Retired Persons (AARP)

Title: End-of-Life Decision-Making

Audience: Consumers

Topic: End-of-life planning

Description: Provides an introduction to end-of-life decision making, information on how to begin the process, what questions to ask, and how to take control of the decision-making process by planning for finances, and medical decisions and care options. Provides information about advance directives, proxies, conservatorships, and guardianships.

Link: <https://caregiver.org/end-life-decision-making>

Reference: Family Caregiver Alliance: National Center on Caregiving

ELDER LAW

Title: Elder Law in Oregon

Audience: Consumers and Professional

Topic: Elder law, financial assistance, medical benefits, advance directive, POLST, Death with Dignity, long-term care, property ownership and rental, protection of legal rights

Description: Provides a handbook that addresses elder law topics including financial assistance, medical benefits, managing financial and health care choice, long-term care, property ownership and rental, and protection of legal rights.

Link: <http://www.oregon.gov/dhs/spwpd/sua/docs/elder-law-handbook.pdf>

Reference: Legal Aid Services of Oregon

Title: Oregon Law Help

Audience: Consumers

Topic: Elder law

Description: Provides information about legal issues and problems including protection from abuse, family and housing issues, consumer and taxes, work, government benefits, and issues faced by seniors and people with disabilities.

Link: <http://oregonlawhelp.org/>

Reference: OregonLawHelp.org

HOSPICE AND PALLIATIVE CARE

Title: National Hospice and Palliative Care Organization

Audience: Consumers

Topic: Palliative care, hospice

Description: Provides information to consumers about choosing a hospice and finding a palliative care provider. Includes a number of other resources including regulatory related information, advocacy work, quality measures, and other resources related to hospice and palliative care.

Link: www.nhpco.org

Reference: National Hospice and Palliative Care Organization

Title: Advance Care Planning – Palliative Care

Audience: Consumers

Topic: Advance care planning, end-of-life care

Description: A video of Joanne Lynn, Bureau Chief for Chronic Disease and Cancer in Community Health Administration of the Department of Health, talking about the importance of advance care planning as a way to improve the quality of life of individuals at the end of life.

Link: <https://www.youtube.com/watch?v=OOH5hVQRxD4>

Reference: Canadian Virtual Hospice

ETHICAL ISSUES RELATED TO END OF LIFE PLANNING

Title: Legal and Ethical Issues

Audience: Consumers

Topic: Advance care planning, legal and ethical issues related to end-of-life planning

Description: Provides information about advance care planning including decision making, and mental capacity, key points about advance care planning, and definitions.

Link: <http://dyingmatters.org/page/legal-and-ethical-issues>

Reference: Dying Matters

DEMENTIA AND ALZHEIMER'S DISEASE

Title: ADRC Dementia Training

Audience: Professionals

Topic: ADRC, dementia, web-based training

Description: Web-based trainings developed by Portland State University. Provides information about person-centered dementia support, communication and behavioral expression in people experiencing dementia, medical and clinical aspects, information and referral issues, and decision support tools for person-centered planning, care transitions, and advance care and end of life planning.

Link: <http://www.oregon.gov/dhs/spwpa/Pages/sua/AvailableOnlineTraining.aspx>

Reference: Oregon APD

Title: End-of –Life Planning

Audience: Consumers and Professionals

Topic: End-of-life planning, Alzheimer's disease

Description: Provides information about treatments, DNR, Hospice, and acknowledging individual's wishes.

Link: <http://www.alz.org/i-have-alz/end-of-life-planning.asp>

Reference: Alzheimer's Association

DISCUSSING END OF LIFE ISSUES

Title: The Conversation Project

Audience: Consumers

Topic: End-of-life planning, end-of-life care

Description: A tool for consumers to learn how to talk to their families and others about end-of-life planning and end-of-life care decisions.

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

Reference: The Conversation Project

Title: The Good-to-Go Resource Guide

Audience: Consumers

Topic: Advance directive, end-of-life planning

Description: Provides a variety of information related to end-of-life planning including information about completing an advance directive. Provides information on how to talk to family and healthcare providers about end-of-life planning. Includes specific information about end-of-life planning for individuals in the LGBTQ community.

Link: <http://www.compassionandchoices.org/userfiles/Good-To-Go-Resource-Guide.pdf>

Reference: Compassion & Choices

Title: The Good-to-Go Resource Toolkit

Audience: Consumers

Topic: Advance directive, end-of-life planning

Description: This is a supplementary toolkit that goes along with The Good-to-Go Resource Guide (above). Includes a variety of worksheets and forms to help guide the process of end-of-life planning including a Values Worksheet, My Particular Wishes Tool, and a hospital visitation form.

Link: <https://www.compassionandchoices.org/userfiles/G2G2015.pdf>

Reference: Compassion & Choices

Title: Your Conversation Starter Kit

Audience: Consumers

Topic: End-of-life planning, end-of-life care

Description: This starter kit is for individuals preparing to have conversations about end-of-life planning and end-of-life care with their family and loved ones. Includes information about end-of-life planning options and guides individuals through the process of thinking about end-of-life care with open ended questions.

Link: http://theconversationproject.org/wp-content/uploads/2015/05/TCP_StarterKit_2015_Final_Writeable.pdf

Reference: The Conversation Project

Title: How to Talk to Your Doctor (or any member of your health care team)

Audience: Consumers

Topic: End-of-life planning, end-of-life care

Description: This starter kit is for individuals preparing to have conversations about end-of-life planning and end-of-life care with their healthcare providers. Includes information about end-of-life planning options and guides individuals through with example questions and conversations.

Link: <http://theconversationproject.org/wp-content/uploads/2013/01/TCP-TalkToYourDoctor.pdf>

Reference: The Conversation Project

II. Brochures, Pamphlets, and Booklets

Title: Making Medical Decisions for Someone Else: A How-To Guide

Audience: Consumers

Topic: End-of-life planning

Description: Provides information on what it is like to be a health care proxy, steps to follow in making medical decisions, working with the health care system, resolving disputes and getting help, and some common situations faced by proxies.

Link:

http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_bk_proxy_guide_gen.authcheckdam.pdf

Reference: The American Bar Association Commission on Law and Aging

Title: Consumer's Toolkit for Health Care Advance Planning

Audience: Consumers and Professionals

Topic: Advance planning

Description: Provides a toolkit for consumers making decisions about their advance health care plans. The toolkit includes information on how to select your health care agent/proxy, terminal illness, weighing odds of survival, evaluating person priorities and spiritual values, a proxy quiz for families and physicians, what to do after signing a health care advance directive, a guide for health care proxies, and additional resources for advance planning for health care.

Link:

http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning.html

Reference: American Bar Association

Title: Assessing Decision Making Capacity (DMC)

Audience: Professionals

Topic: Capacity

Description: A pamphlet that provides information about how to assess the decision making capacity (DMC) of patients.

Link: <http://www2.med.psu.edu/humanities/files/2013/07/Assessing-Decision-Making-Capacity.pdf>

Reference: Penn State Milton S. Hershey Medical Center

III. Journal Articles

Advance Directives

Title: Completion of Advance Directives among U.S. Consumers

Audience: Professionals

Topic: Advance directives

Description: This article provides results about the number of individuals who have completed advance directives nationally. The authors also try to draw conclusions about the relationship between demographic and socioeconomic variables and likelihood to complete an advance directive.

Link to article: [http://www.ajpmonline.org/article/S0749-3797\(13\)00521-7/abstract](http://www.ajpmonline.org/article/S0749-3797(13)00521-7/abstract)

Reference: American Journal of Preventive Medicine

Mental Health

Title: Mental Health and Palliative Care Literature Review

Consumers: Professionals

Topic: Mental health, palliative care, literature review

Description: Literature review of research conducted around palliative care related to individuals with mental health problems.

Link to article:

http://www.mentalhealth.org.uk/content/assets/pdf/publications/mental_health_palliative_care.pdf

Reference: Mental Health Foundation

Title: Palliative Care for People with Severe Persistent Mental Illness: A Review of the Literature

Consumers: Professionals

Topic: Palliative care, literature review, mental health

Description: Literature review of research conducted around palliative care related to individuals with severe persistent mental illness (SPMI).

Link to abstract: <http://www.ncbi.nlm.nih.gov/pubmed/19087466>

Reference: Canadian Journal of Psychiatry

Title: End-of-Life Treatment Preferences of Persons with Serious Mental Illness

Audience: Professionals

Topic: End-of-life care, mental health

Description: This article provides results based on The Health Care Preferences Questionnaire about the preferences for end-of-life treatment for individuals with a serious mental illness.

Link to article: <http://ps.psychiatryonline.org/doi/full/10.1176/appi.ps.56.5.585>

Reference: Psychiatric Services

Capacity

Title: Does This Patient Have Medical Decision-Making Capacity?

Audience: Professionals

Topic: Capacity, end-of-life treatment

Description: This article provides results based on the secondary analysis of the capacity of patients in medical decision-making.

Link to abstract: <http://www.ncbi.nlm.nih.gov/pubmed/21791691>

Reference: Journal of the American Medical Association