

Resources

Advance Care Planning

- **Caring Connections** <http://www.caringinfo.org>
This is a useful site for patients and families. It offers useful concrete information and guide regarding advance directive, health care agents, hospice care, caring for a loved one at home (including a child), financial planning and grief support. It also has useful links for community outreach programs. (8/10)

- **Gold Standard Framework for Palliative Care** <http://www.goldstandardsframework.nhs.uk>
The Gold Standard Framework (GSF) is part of National Health Services End of Life Program in England. Aim is to improve care for the dying in the community by promoting development of quality, proactive, coordinated palliative care within local areas. Provides information on the principles behind GSF and educational materials for primary care physician on symptom control and prognostic indicator guidance in palliative care. (7/10)

- **Handbook for Mortals** <http://www.medicaring.org>
This is the "Palliative Care Policy Center" website which has links to online excerpts and summaries from Joanne Lynn's *Handbook for Mortals*, *Sick to Death*, *Improving Care for the End of Life*, and *Improving Palliative Care*. It also has some useful caregiver guides for CHF and COPD. (5/10)

- **POLST** <http://www.ohsu.edu/ethics/polst>
Website sponsored by OHSU, Oregon Health & Science University
POLST: Physician Orders for Life-Sustaining Treatment Paradigm, first developed in Oregon. It provides information on history of development of POLST Paradigm, useful information for health care professionals and patients and families who are interested in learning more about POLST. It also has materials that can facilitate the development of POLST Paradigm programs in your state. (7/10)

- **Respecting Choice Program/Gunderson Lutheran** La Crosse, Wisconsin
<http://gundluth.org/eolprograms>
It provides information on an Advance Care Planning Program developed by the Gundersen Lutheran health care system in Wisconsin. It may be useful for organizations and communities who are interested in setting up similar programs. It provides courses and educational materials. (5/10)

- **Vermont Ethics Network** <http://www.vtethicsnetwork.org>
The website has an FAQs section that provide some good and basic answers to questions regarding Advance Directive and Health Care Agent. It also has a link to the Vermont Directive Registry; useful to residents of Vermont. (5/10)

Beyond Quality Improvement

- **Americans for Better Care of the Dying** <http://www.abcd-caring.org>
(7/10) Americans for Better Care of the Dying (ABCD) was founded in 1997, aimed at building momentum for reform, exploring new methods and systems for delivering care and shaping public policy through evidence-based understanding. While the website mainly focuses on public policy reform, it also has a very comprehensive and useful Links section on topics like advance care planning, end-of-life, hospice and palliative care, and grief and bereavement.

Building a Palliative Care Program

- **National Consensus Project for Quality Palliative Care** <http://www.nationalconsensusproject.org>
The NCP was created to promote the implementation of clinical practice guidelines that would ensure consistent and high quality palliative. You can find the current guidelines in the website but not a lot of practical information for building a palliative care program. (7/10)
- **The Center to Advance Palliative Care** <http://www.capc.org>
This website is a one-stop-shop for tools, training and technical assistance necessary to start and sustain a successful palliative care program in hospitals and other health care settings. A useful feature of the website is the downloadable PowerPoint™ presentations on many topics that have been presented at previous conferences. (10/10)

Caring for Caregivers

- **Aging Parents and Elder Care** <http://www.aging-parents-and-elder-care.com>
Developed by a layperson, the website serves its purpose as a comprehensive resource center for people who are taking care of an elderly loved one. It provides information and solutions to lots of practical and day-to-day challenges faced by the caregivers. Topics range from home safety, living arrangements, prescription drug reference, choosing a nursing home/assisted living facility, to medical supplies and home health care products. Useful website links and a very active online support group. (8/10)
- **Caring Connections** <http://www.caringinfo.org>
This is a useful site for patients and families. It offers useful and concrete information and guide regarding advance directive, health care agents, hospice care, caring for a loved one at home (including a child), financial planning and grief support. Has community outreach programs links. (8/10)

- **Family Caregiver Alliance** <http://www.caregiver.org>

Founded in 1977, Family Caregiver Alliance was the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home. It is a fairly easy website to navigate and has different sections on Public policy & Research, Caregiving Info & Advice, Fact Sheets & Publications, Newsletters and Discussion Groups. Each section provides substantial and practical information for its target audience. (9/10)

- **National Alliance for Caregiving** <http://www.caregiving.org>

The National Alliance for Caregiving, a non-profit coalition of national organizations focusing issues on family caregiving, was established in 1996. It was created to conduct research, do policy analysis, develop national programs and increase public awareness of family caregiving issues. Although the website does contain a caregiver resource section, its main target is policy makers at an organization level. (7/10)

- **National Family Caregiver Support Program (NFCSP)**

Administration on Aging, Department of Health and Human Services

http://www.aoa.dhhs.gov/prof/aoaprogram/caregiver/overview/overview_caregiver.asp

This is the resource room for the National Family Caregiver Support Program (NFCSP). The NFCSP was developed by Administration on Aging (AoA) of the U.S. Department of Health and Human Services in 2000. Serves family caregivers of older adults (>60) and grandparents and relative caregiver of children under age of 18. This is a very useful site to help caregivers and social workers (and other providers) to research information and assistance in gaining access to different supportive services in the community. It also provides lots of resources for caregivers to better cope with their day-to-day challenges and local support groups. Another good feature of this website is the information is also provided in eight other languages-- Chinese, German, Spanish, French, Italian, Japanese, Korean and Portuguese. (7/10)

Continuity and Transfers

- **American Geriatrics Society, Position Statement: Improving the Quality of Transitional Care for Persons with Complex Care Needs** <http://www.americangeriatrics.org>

This is the 2002 AGS position statement on improving the quality of transitional care for persons with complex care needs. (7/10)

The direct link is

http://www.americangeriatrics.org/products/positionpapers/complex_carePF.html

- **Merck Manual of Health and Aging** http://www.merck.com/pubs/mmanual_ha/contents.html

Section 2, chapter 9 of the manual discusses the topic of continuity of care. It also has sections on Hospice Care (chap 11) and Palliative and End-of-Life Care (chap 16). (6/10)

▪ **The Care Transitions Program and Health Sciences Center at the University of Colorado, Denver** <http://www.caretransitions.org>

The Care Transitions Program was developed by the University of Colorado at Denver and Health Sciences Center, aimed at improving the quality and safety of care for persons with complex care needs during the transition from hospital to home. The website provides the detailed description of the program, publications related to the program. It may serve as a useful guide for policy makers, researchers and practitioners who are interested in establishing similar programs. (8/10)

Hospice Program Quality

▪ **42 CFR Part 418. (2005). Medicare and Medicaid Programs: Proposed Conditions of Participation; Proposed Rule**

<http://www.cms.hhs.gov/quarterlyproviderupdates/Downloads/CMS3844P.pdf>

These are the 2005 regulations issued by Center for Medicare and Medicaid Services, detailing requirements that must be met by hospices to participate in the Medicare and Medicaid programs. (10/10)

▪ **Edmonton Symptoms Assessment Scale**

<http://www.promotingexcellence.org/i4a/pages/Index.cfm?pageID=3333>

This is a link to the Edmonton Symptom Assessment Scale, an assessment tool developed for cancer patients. It is a 9-item patient-rated symptom visual analogue scale developed for use in assessing the symptoms of patients receiving palliative care. This scale has been validated in a couple of studies. (8/10)

▪ **Hallenback, J. (2005). Ten Simple Things You Can Do to Access Hospice and Palliative Care Resources.**

http://growthhouse.typepad.com/james_hallenbeck/2005/08/national_consen.html

The article gives ten very useful advices on how to better access resources in hospice and palliative care. It contains information on many recommended textbooks, key journals and useful palliative care websites. (10/10)

▪ **National Institutes of Health. (2004, December). State of the Science Conference Statement on Improving End of Life Care**

<http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm>

Although the statement was made in 2004, the conclusions drawn by the conference on the shortcomings of end-of-life care and recommendations made still very much applicable today. (8/10)

▪ **National Hospice and Palliative Care Organization** www.nhpco.org

The website has a lot of useful links and information for both professionals and consumers. Under Quality Partners section, you will find 10 components of quality in hospice care. Under the Learn

About End-of-Life Care section, consumers can find easy to understand information on many end-of-life care topics. (8/10)

Improving Care for People with Advanced Dementia and their Families

- **Alzheimer's Association Campaign for Quality Residential Care:**

Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes (2005) <http://www.alz.org>

This is a comprehensive website on Alzheimer's dementia, providing educational and practical information for patients, caretakers, family members, clinicians and researchers. (10/10)

- **Caring for a Loved One with Advanced Dementia: A Caregiver's Manual**

<http://www.hom.org>

This is the Hospice of Michigan's website, thus particularly useful and relevant for residents of Michigan. The caregiver's manual is not available online, but can be purchased from the website <http://www.hom.org/mac/maccm.asp> (7/10)

- **NOPPAIN (Non-Communicative Patient's Pain Assessment Instrument)**

By Snow, O'Malley, Kunic, Cody, Beck and Ashton

http://www.sdfmc.org/ClassLibrary/Page/Information/DataInstances/81/Files/339/noppainform_1.pdf

This is a nursing assistant-administered instrument for assessing pain behaviors in non-communicative patients with dementia. It is also available in Spanish. Can be a very useful instrument in nursing home facilities. (8/10)

- **Pain Assessment In Advanced Dementia (PAINAD)**

<http://mqa.dhs.state.tx.us/QMWeb/Pain/PAINAD.htm>

This is a link to the Pain Assessment in Advanced Dementia (PAINAD) Scale. It is often difficult to assess pain in patients with advanced dementia. This scale (although unclear how much it has been validated in practice) can be a useful assessment tool for nursing home facilities. (8/10)

Nursing Home Quality

- **Agency for Healthcare Policy and Research (AHRQ)**

<http://www.ahrq.gov/clinic/cpgonline.htm>

This is not a very easy website to navigate. Its main target seems to be for health care policy makers. Includes 19 clinical practice guidelines (not all current) developed by the agency and evidence reports on different topics through literature review. (5/10)

- **Braden Scale** for predicting pressure ulcers <http://www.bradenscale.com/braden.PDF>

This scale is one of the most widely used tools for predicting the development of pressure ulcers and has been validated in several studies. (8/10)

- **National Pressure Ulcer Advisory Panel** <http://www.npuap.org>
This is the panel responsible for the development of PUSH tools. In addition to obtaining information on pressure ulcer staging, prevention and treatment, you can also find information on public policy and research regarding pressure ulcers. (8/10)
- **PUSH Tool** for monitoring pressure ulcers <http://www.npuap.org/PDF/push3.pdf>
This is a useful scale developed by National Pressure Ulcer Advisory Panel to monitor the healing process of pressure ulcers. It may be particularly useful tool for nursing home facilities. The National Pressure Ulcer Advisory Panel website also has information on pressure ulcer staging, prevention and treatment. (8/10)

Preventing, Assessing, and Treating Pain and Symptom Management Tools

- **Assessing Pain in Persons with Dementia**
<http://www.hartfordign.org/publications/trythis/assessingPain.pdf>
This is another link endorsing the Pain Assessment in Advanced Dementia (PAINAD) Scale. (8/10)
- **City of Hope Pain/Palliative Care Resource Center** <http://mayday.coh.org>
An easy to navigate website maintained by City of Hope. It provides a variety of materials including different pain assessment tools, patient education materials, quality assurance materials, end of life resources and research instruments. Has a section for Special Populations which includes Pediatrics, HIV/AIDS patients, Cultural considerations, family caregivers, etc. (9/10)
- **Department of Pain Medicine and Palliative Care, Beth Israel Medical Center**
<http://www.stoppain.org>
Beth Israel Medical Center Pain Medicine and Palliative Care website. It is an extremely easy and pleasant website to navigate. Its main target is the general public. Provides lots of information on chronic pain and different treatment options. Also includes sections on palliative care, hospice, and chemical dependency. Has a section “For Professionals” which provides some educational materials. The slide compendium for topics in pain management is particularly useful. (8/10)
- **Edmonton Symptom Assessment System (ESAS)**
<http://www.palliative.org/PC/ClinicalInfo/AssessmentTools/esas.pdf>
This is a link to the Edmonton Symptom Assessment Scale, an assessment tool developed for cancer patients. It is a 9-item patient-rated symptom visual analogue scale, developed to assess the symptoms of patients receiving palliative care. This scale has been validated in a couple of studies. (8/10)

- **Growth House** <http://www.growthhouse.org>

Website has a very useful search engine. You can basically look up any topic on end-of-life care from its mega search engine and be provided with tons of educational information from its IICN (Inter-Institutional Collaborating Network on End of Life Care) Public Library database. Main target is professionals of all disciplines who participate in the end of life care. (8/10)

- **ICU Delirium and Cognitive Impairment Study Group: Brain Dysfunction in Critically Ill Patients** <http://www.icudelirium.org/delirium>

Good website for clinicians and general public to learn about ICU delirium (including assessment and treatment), but does not provide much information on palliative and end-of-life care. (5/10)

- **National Center for Complementary and Alternative Medicine**

<http://www.nccam.nih.gov>

This is a comprehensive website for clinicians or general public who are interested in learning about complementary and alternative medicine, sponsored by NIH. For clinicians, there are information and links to research opportunities, clinical trials and training opportunities. For general public, there are lots of useful and easy-to-understand fact sheets explaining different CAM treatments and therapies. (8/10)

- **Pain Assessment in Advanced Dementia (PAINAD)** (Five item observational tool for caregivers) <http://mqa.dhs.state.tx.us/QMWeb/Pain/PAINAD.htm>

This is a link to the Pain Assessment in Advanced Dementia (PAINAD) Scale. It is often difficult to assess pain in patients with advanced dementia. This scale (although unclear how much it has been validated in practice) can be a useful assessment tool for nursing home facilities. (8/10)

- **Partners Against Pain** <http://www.partnersagainstpain.com>

The main focus of this website is non-cancer pain. It includes a variety of pain assessment tools and a useful Opioid Therapy Documentation Kit to help physicians evaluate and select patients appropriate for opioid therapy for chronic pain. (5/10)

- **Promoting Excellence In End of Life Care** (Clinical Assessment Tools/Symptoms Management) <http://www.promotingexcellence.org/i4a/pages/index.cfm?pageid=3276>

This is a comprehensive website that covers a lot of information on end of life care. Very easy to navigate and includes four main categories: Clinical Care Tools, Educational Tools, Evaluation Tools and Organizational Tools. Provides useful information for all disciplines that participate in the end of life care, clinicians, social worker, spiritual guides and administrators. Gives concrete guide from advance care planning, delivering bad news to symptom managements (like how to prevent and care for pressure ulcers). Patient/Family Education section is particularly helpful. Provides easy to understand information on different disease

processes, symptom managements, utility and futility of CPR and mechanical ventilations, hospice care, and practical tips on performing ADLs and IADLs. (10/10)

- **Wong/Baker FACES Scale** <http://www3.us.elsevierhealth.com/WOW/faces.html>

The Wong/Baker Faces pain scale can be useful for pediatric and nonverbal patient population to communicate how much pain they are experiencing. (5/10)

Use this link for the Wong-Baker Faces Pain Rating Scale:

http://www.mdanderson.org/pdf/pted_painscale_faces.pdf