

*Websites of interest
to end-of-life researchers and policy-makers*

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Websites of interest to end-of-life researchers and policy-makers

[End of Life / Palliative Education Resource Center \(EPERC\)](http://www.eperc.mcw.edu/start.cfm)

<http://www.eperc.mcw.edu/start.cfm>

Online community of educational scholars; includes Peer Reviewed Educational Materials by End of Life Topic

End of Life/Palliative Education Resource Center Weekly E-News

This newsletter is sent to more than 5000 subscribers as a service of the End of Life/Palliative Education Resource Center . Anyone can subscribe by registering at <http://www.eperc.mcw.edu>

[End of Life: Schedule and Transcripts](http://www.npr.org/programs/death/trns.html)

<http://www.npr.org/programs/death/trns.html>

Audio and text files of NPR (National Public Radio) programmes on a wide variety of topics of interest to death & dying studies.

[BBC News | In Depth | Health | Euthanasia](http://news.bbc.co.uk/1/health/2001/euthanasia/default.stm)

<http://news.bbc.co.uk/1/health/2001/euthanasia/default.stm>

Special reports, including case studies from BBC radio.

DIPEX

<http://www.dipex.org/EXEC>

The DIPEX website is aimed at patients, their carers, their family and friends and health professionals. It is a unique resource and one that will be extended to include modules on over 100 diseases, as well as modules on health related matters such as pregnancy screening, immunisation, palliative care, children of parents with cancer, all of which DIPEX hopes to achieve within the next 5 years. You can watch, listen to or read their interviews, learn more about the illness and its treatments as well as where to find support and more detailed medical information. Current modules include: Hypertension, Prostate cancer, Breast cancer, Colorectal cancer, Testicular cancer, Cervical screening and cancer.

The National Council for Hospice and Specialist Palliative Care

<http://www.hospice-spc-council.org.uk/index.htm>

The National Council for Hospice and Specialist Palliative Care is the "representative and coordinating body for all those involved in hospice and specialist palliative care in England, Wales and Northern Ireland". The site provides details about the Council, and their publications, with some full-text documents available online. They also provide a directory of hospice and specialist palliative care services in the UK and Republic of Ireland, and links to other relevant resources.

Growth House

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

This is a subject gateway to palliative care and end of life resources on the Internet, aimed at those with a life threatening illness. It is produced by Growth House, who aim to "improve the quality of compassionate care for people who are dying through public education about hospice and home care, palliative care, pain management, death with dignity, bereavement, and related end of life topics." Information for professionals is also included. Links are provided to various resources in the fields of palliative care, pain management, hospice and home care, death with dignity, improving the quality of care, grief and bereavement, bereaved families, natal and infant loss, helping children with grief and serious illness, and a number of major illness resources. These resources are fully

described and rated. There is also a chat room, online bookstore and free monthly e-mail newsletter. Published by Growth House Inc., a not-for-profit California corporation.

Help: Helpful Essential Links to Palliative Care

<http://www.dundee.ac.uk/meded/help/welcome.htm>

Identifies the common problems in palliative care and provides the key information needed to tackle the problems. Resource material is provided on pain, communication, distressing symptoms and context of care using a problem-based approach suitable for both doctors and patients. A detailed alphabetical index facilitates the use of the resources. This site is part of a programme being undertaken by the Centre for Medical Education, University of Dundee, in collaboration with the Cancer Relief Macmillan Fund (CRMF).

Help the Hospices

<http://www.helpthehospices.org.uk/>

A UK based charity that is "dedicated to the care and comfort of the terminally ill". This site provides information about the charity, grants, education and training, regional and outreach training guidelines, central courses, and links to other sites. Also included is a searchable database of hospice addresses, numbers and details in the UK.

Hospice History Project

<http://www.hospice-history.org.uk/>

Housed at the University of Sheffield; Aims: to undertake and to foster academic study in the history of hospices, palliative care and related fields; To catalogue and help safeguard archival records relevant to hospice and related developments in Britain and Ireland; to establish a hospice and palliative care digital archive.

Innovations in End-of-Life Care: Palliative Practices/Tools.

<http://www2.edc.org/lastacts/>

An international journal of leaders in end-of-life care; searchable archives. Useful Tools found in Innovations in End-of-Life Care online, by category; includes Spirituality Assessment Tool. Areas:

[Assessing Patients' Experience](#)

[Relieving Pain](#)

[Creating Systems of Care/Training](#)

[Curricular Materials/Training](#)

[Standards](#)

[For Families and/or Patients](#)

Also see: <http://www2.edc.org/lastacts/archives/archivesSept00/resources.asp>

TIME: Toolkit of Instruments to Measure End-of-life care

<http://www.chcr.brown.edu/pcoc/toolkit.htm>

A fundamental barrier in the quality of care at the end of life is the lack of measurement tools. These measurement tools should identify opportunities for improving medical care, examining the impact of interventions or demonstration programs, and holding institutions accountable for their quality of care. The Toolkit takes steps toward crossing this measurement barrier by creating patient-focused, family-centered survey instruments that address the needs and concerns of patients and their families, as defined by them.

[Executive Summaries of the TIME Conferences](#)

[Annotated Bibliographies of Existing Instruments](#)

[Guidance on Choosing a Measurement Instrument](#)

[New Validated Instruments](#)

[Resource Guide for Using Toolkit Instruments](#)

[Old Draft Instruments](#)

[Slide Presentation: Conceptual Model of Patient Focused Family Centered Medical Care](#)

[Links to other Web Sites](#)

[Search other palliative care sites with the Growth House Search Engine](#)

NEW VALIDATED INSTRUMENTS Patient Focused, Family Centered Care
<http://www.chcr.brown.edu/pcoc/NEWVALIDATEDINSTRUM.HTM>

- [After-death Bereaved Family Member Interview](#)
- [Prospective Patient Interview](#)

[End of Life / Palliative Education Resource Center \(EPERC\)](#)

<http://www.eperc.mcw.edu/start.cfm>

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[Last Acts campaign to improve end-of-life care](#)

<http://www.eperc.mcw.edu/start.cfm>

Last Acts is a campaign to improve end-of-life care by a coalition of professional and consumer organizations (US).

Education for Physicians on End-of-Life Care [EPEC.net](#)

<http://www.epec.net/>

Includes Kit's Legacy: Kit Meshenberg, the former Administrative Director of The EPEC Project, documented her own personal battle with cancer. <http://kitslegacy.org/index.cgi?id=77>; includes photos and audio files.

Palliative Care Australia: Multicultural palliative care guidelines

<http://www.pallcare.asn.au/mc/mccontents.html>

A desire to educate the community about palliative care falters at the doorstep of Non English Speaking Background (NESB) groups. An inability of some Australians to read English is just the first stumbling block. Cultural attitudes and traditions create a tricky path, requiring a delicate tread. Being informed that the words Death, Dying and Cancer are taboo for many cultures creates immediate difficulties in discussing palliative care. Includes Language Groups: [Arabic](#) | [Bosnian](#) | [Chinese](#) | [Croatian](#) | [Greek](#) | [Hindi](#) | [Italian](#) | [Japanese](#) | [Khmer](#) | [Korean](#) |

[Macedonian](#) | [Maltese](#) | [Persian](#) | [Polish](#) | [Portuguese](#) | [Russian](#) | [Serbian](#) | [Spanish](#) | [Turkish](#) | [Vietnamese](#)

[Promoting Excellence in End-of-Life Care: Palliative Care, Death, Dying](http://www.promotingexcellence.org/)

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

“Dedicated to long-term changes to improve health care for dying persons and their families through technical assistance to [innovative demonstration projects](#) addressing particular challenges to existing models of hospice and palliative care”.

Center to Advance Palliative Care [CAPC](#)

<http://www.capcmssm.org./index.cgi?tnav=1>

Mission is to increase the availability of quality palliative care services in hospitals and other healthcare settings for people with life-threatening illnesses, their families and caregivers. Includes the extensive annotated bibliography, *Last Acts Diversity and End-of-Life Care Literature Review* <http://www.capcmssm.org./content/105/>, which includes both qualitative and quantitative studies, and American and global perspectives.

American Association of Colleges of Nursing End-of-Life Nursing Education Consortium (ELNEC)

Project [AACN - ELNEC Project](#)

<http://www.aacn.nche.edu/elneec/>

The End-of-Life Nursing Education Consortium (ELNEC) project is a comprehensive, national education program to improve end-of-life care by nurses, and is funded by a major grant from [The Robert Wood Johnson Foundation](#). Primary project goals are to develop a core of expert nursing educators and to coordinate national nursing education efforts in end-of-life care.

Palliative Care Key Sites University of Toronto

<http://dfcm19.med.utoronto.ca/library/palcare%20links.htm>

University of Toronto, Department of Family and Community Medicine, Selected Links to Palliative Care - Death/Dying - Hospice Care - Terminal Care - An Annotated list -

[Project on Death in America - Transforming the Culture of Dying](http://www.soros.org/death/)

<http://www.soros.org/death/>

The mission of the Project is to understand and transform the culture and experience of dying and bereavement through initiatives in research, scholarship, the humanities, and the arts and to foster innovations in the provision of care, public education, professional education, and public policy. The big funder of projects in the US.

Ian Anderson Continuing Education Program in End-of-Life Care

<http://www.cme.utoronto.ca/endoflife/Overview.htm>

Program in End-of-Life Care will educate 10,000 primary care physicians and specialists across Canada over a five-year period to deal with issues surrounding death and dying. It will also hold conferences relevant to dying in critical sectors including healthcare institutions and educators, media and government. Downloadable pdf and powerpoint teaching aides.

End-of-life research: What we know and what we don't, James L Werth, Jr

<http://www.uakron.edu/eol/adobe/eolrefs.pdf>

References include section on Cultural Considerations (19).

On Our Own Terms: Moyers on Dying - Home

<http://www.pbs.org/wnet/onourown/terms/index.html>

On Our Own Terms: Moyers on Dying [RealPlayer, .pdf] Bill Moyers, well-known American TV journalist's programme on Dying with follow-up discussion transcripts, resources, etc.

The website contains four principal sections. 1. End-of-life-tools 2. Care options 3. Final days 4. Therapy & support. In these sections you will find articles and resources to help patients and their families prepare for the end of life.

Beyond Indigo (Formerly Death-Dying.com)

<http://www.death-dying.com>

This site is privately owned and funded by the owner and advertising on its pages. In a sensitive fashion, topics such as loss, near-death experiences, and terminal illness are explored through essays and personal insights. There are pages dedicated to kids and another to teens. The site also has inspirational poetry, and information on health and legal issues associated with death.

Doctor-Assisted Suicide The Longwood College Library

<http://web.lwc.edu/administrative/library/suic.htm>

"A guide to WEB Sites and the Literature." The site provides an extensive bibliography of resources about physician-assisted suicide from ethical, legal, religious, psychological, philosophical, and public policy points of view. In addition you can find information on general care, hospice care, palliative care and home care. Also covered are topics on physician assisted suicide, cultural traditions and planning a funeral. The last section discusses grief and grief counseling and the healing arts.

The Cambridge and Huntingdon Palliative Care Group's Palliative Care Resource Folders

<http://www.pallcareresource.demon.co.uk/>

The pages contain palliative care information published in the new Community Palliative Care Resource Folders, which have been distributed to General Practitioners throughout Cambridgeshire.

The National Center for Cultural Healing

<http://www.culturalhealing.com/>

NCCH training and technical assistance staff can join with your organization to lay a foundation and develop frameworks for group success, results-oriented learning, purposeful change, and cultural healing and well being. Health And Culture: Issues in Cultural Competency Bibliographic

References <http://www.culturalhealing.com/resources.htm>

Edmonton Regional Palliative Care Program

<http://www.palliative.org/PC/RPCP/RPCPIdx.html>

The Regional Palliative Care Program (RPCP) is a community based model of palliative care services designed to increase access to high quality, cost effective palliative care services. The program has focused on providing access to palliative care support in the home and in all region health care institutions, while shifting the main area of end-of-life care from acute care, to home and hospice (hospices are in continuing or long term care facilities). As outlined in the objectives, the program addresses clinical, educational, research and operational areas.

The Sheffield Palliative Care Studies Group (SPCSG)

<http://www.sheffield-palliative.org.uk/>

The University of Sheffield's Academic Palliative Medicine Unit, based in the School of Medicine, has received a research grant of £390,000 to explore ways of opening up access to palliative care for potential patients and carers who are presently excluded. The two-and-a-half-year project is funded by a London charitable trust. Professor Sam Hjelmeland Ahmedzai (Chair of Palliative Medicine) is Director of SPCSG and Professor David Clark (Chair of Medical Sociology) is Associate Director. Other senior staff include Professor Sheila Payne (Chair of Palliative Care Nursing) and Dr Bill Noble (Macmillan Senior Lecturer). The SPCSG is responsible for a wide range of academic and clinical activities. Its multi-disciplinary research programme includes clinical trials, needs assessment and service evaluations, methodological development, information services, historical and cultural studies.

King's College- University of London Department of Palliative Care and Policy

<http://www.kcl.ac.uk/depsta/palliative/welcome/welcome.html>

A multi-professional department comprising two Professors (one clinical and one non-clinical), one Clinical Senior Lecturer, a Lecturer, around 20 multi-professional research, education and support staff and consultants in the three main hospitals to which our Medical School is partnered, Guy's and St Thomas' NHS Trust, and King's College Hospital. We also have collaborations and shared appointments with many palliative care teams, hospices and related services in the UK and overseas and with colleagues in Schools throughout King's College London, including Medicine, Biomedical Sciences, Dentistry, Nursing and Midwifery, Law and Ethics, the Institute of Psychiatry and the Humanities.

CultureMed: Death and Dying in Multicultural Perspective

<http://www.sunyit.edu/library/html/culturedmed/bib/dd/>

Bibliography compiled by Jacquelyn Coughlan, M.S., M.L.S., State University of New York, Institute of Technology

APA Online: End-of-life Issues and Care Diversity Issues in End-of-life Decision-Making

<http://www.apa.org/pi/eol/diversity.html>

Social and cultural groups vary with regard to beliefs and opinions regarding end-of-life decision-making. This includes the appropriateness of talking about and planning for death, informing persons that they are dying, and the roles of the individual, family members, and physicians regarding end-of-life decisions. These groups also vary in even more basic dimensions (such as

orientation to the future, conceptions of the self and personhood, and beliefs about the rights of the individual) that may have implications for end-of-life decision-making. In addition, individual differences within social groups can be as great as, or greater than, differences between groups because individuals are often exposed to multiple and sometimes contradictory systems of values.

DyingWell Organisation

<http://www.dyingwell.com>

Dr. Ira Byock, long time palliative care physician and advocate for improved end-of-life care, and a past president of the American Academy of Hospice and Palliative Medicine, provides written resources and referrals to organizations, web sites and books to empower persons with life threatening illness and their families to live fully.

University of Michigan Selected Bibliography of Grief and Bereavement Resources in the Social Work Library, with Selected Web Resources

<http://www.lib.umich.edu/socwork/bereavement.html>

[Reference Books](#) ** [Books](#) ** [Journals](#) ** [Databases](#) ** [Videos](#)
** [Other Libraries](#) ** [Web Resources](#)

Cross-cultural Counseling In Disaster Settings

<http://www.massey.ac.nz/~trauma/issues/1999-2/doherty.htm>

This article reviews cross-cultural counseling, presents a review of a number of studies involving disaster victims and workers in other cultures and presents information about cross-cultural aspects of grief. It discusses some general methods and approaches that disaster mental health professionals should consider when contemplating providing disaster mental health services outside of their own culture. Emphasis is made that collaboration with providers and/or "culture-brokers" from the culture should be sought. Most common findings across cultures for those affected by disasters was that most symptoms of victims were those associated with PTSD, depression, and anxiety disorders. Understanding the role of families is discussed as well as effects of disasters on children. The research and literature suggest that children are at risk for PTSD, depression, and anxiety disorders as well as developmental delays as a result. Sensitivity in dealing with grief and grief rituals across cultures is emphasized. The development of an international disaster mental health services model with a strong emphasis on cross-cultural factors, consultation, collaboration, and education is suggested as a method to help mitigate and plan appropriate responses to disaster related mental health responses and problems.