MLA 2003 Cancer Librarians Section Program

*Through Tempests and Storms: Vaccines, Biologicals, Patient Education, and Environmental Health*

What are the latest issues and historical background of the current resurgence of interest in vaccines? What effects has this had on consumers and patients? How do biological agents and research show promise for medical uses and threat for military ones? How do both of these relate to environmental toxicology and health? Most importantly, what do they have to do with your library? The papers will showcase creation and sources of information on vaccines and immunization, biologicals, patient education and environmental health issues. Find out more by attending the program on Vaccines, Biologicals, Patient Education and Environmental Health.

*Primary Section Sponsor:* Consumer and Patient Health Information.

*Secondary Section/SIG Sponsors:* Cancer Librarians, Pharmacy and Drug Information, Molecular Biology and Genomics SIG, Public Health/Health Administration, Chiropractic Libraries

*Type of Program:* Combination (Contributed with possible Invited Speaker).

Papers on issues of vaccines, biologicals, and environmental health, as they relate to health care, library services and collections, consumer and patient health information, and informatics.
Cancer Librarians Section Business Meeting Minutes
MLA Annual Meeting in Dallas
May 21, 2002


The meeting was called to order at 1:20 by Halyna Liszczynskyj. Copies of the minutes of last year's meeting and of the agenda were distributed. The minutes were approved as written.

President's & Treasurer's Report:
The President's Report is appended below. The Treasurer's Report was presented by Cheryl Warren for Sharon Lezotte. There is a current balance of $5122.08. Thanks to the Molecular Biology SIG for fundraising a donation of $1250 from Elsevier for the program we co-sponsored. Sharon reported that she had problems setting up an organizational bank account. She suggested that we establish a money market account with Vanguard, so that section funds stay in one place, regardless of treasurer. Her suggestion was approved.

Elections & Nominating Committee Report:
Karen Albert thanked the members of the nominating committee, Ann Marie Clark and Cheryl Warren, for their work. Gail Hendler was elected Section Council Representative-Elect, and Annelie Sober remains Section Council Representative. Margaret Vugrin was elected Chair-Elect; Halyna Liszczynskyj becomes Chair and Gail Ablove becomes Past-Chair. Sue Felber remains Secretary. Karen asked about the possibility of voting electronically. Jerry Perry, as MLA Board representative, said that ballots can go out electronically but may not be returned that way.

Bylaws Report:
Karen reported that the bylaws had been revised and reviewed by section officers, using the MLA model of bylaws, and then distributed to all section members for comments. Halyna moved that the revised bylaws be accepted. Margaret Vugrin seconded the motion, and the motion carried. It was decided to place a copy on the web site.

Webmaster Report:
The Webmaster's report was presented by Ann Marie Clark. She thanked the newsletter editor, Tanya Smith, and requested any ideas for additional web content be sent to herself. A discussion about advertisements on the web site and on the listserv ensued. Jerry Perry commented that MLA would be producing a policy for advertising on their web sites. Any decision was deferred until Ann Marie contacts MLA for information about their advertising policy and about corporate sponsorship of web sites. Annelie Sober suggested that any product information for the listserv should be posted by an individual member, not by the section as a whole, and that was approved. Jerry asked if the section had any interest in putting the web site on MLA.net. It was decided to table that question until further information about fees and policies can be answered.

Newsletter Editor Report:
Tanya Smith reported that the newsletter has been published twice in the last year, and that she is now the sole editor. The newsletter needs article submissions, so please keep that in mind. A discussion of advertising in the newsletter occurred, and it was decided that Karen Albert would approach MLA for the guidelines about this. Tanya was given authorization to distribute promotional information about an NCI video set she received in April.

2003 Section Program Chair:
Margaret Vugrin reported as Program Chair on next year's program. The theme is "Catch the Wave" and the program will be six concurrent sessions of 90 minutes. Each portion will be 20 minutes, and then folks can move to other presentations as desired. Other groups wanting to partner with Cancer Section are Pharmacy Section and Molecular Biology SIG. Pharmacy proposes a session on vaccines and biologicals. Other possible topics were fundraising, branding, e-journal management, evidence-based research, bioterrorism, access to healthcare for minorities, zoonoses, public health informatics, collection management issues, and virtual training. After discussion, it was decided to co-sponsor the program on vaccines and biologicals with the Pharmacy section.

Continued on page 3
Core Cancer List:
The Core Cancer list was discussed, and Cheryl Warren reported that it had been updated last year and is now on the web site. Halyna thanked Cheryl for her work on this project on behalf of the Section. Margaret Vugrin asked if another annotated list was planned. The annotated list produced revenue for the section in years past. Margaret volunteered to lead a group to investigate how this type of project could be done and ways to produce the list. She asked for volunteers to help review and annotate entries. Karen Albert will contact MLA to find out about publication options within MLA.

Section Council News:
Annelie Sober reported on Section Council News. She mentioned several name changes for sections and SIGs that were approved. Hospital Libraries standards have been approved. The Daniel T. Richards Prize has been amended to two years for submission, and that in the case of multiple authors, each author would be given a certificate. Communications Committee has suggested a logo for Section Council, and that was distributed for discussion. The question of printing the proposed logo in color was raised, and Annelie will share this concern with Section Council. She asked for input on individuals being considered for MLA nominating committee.

New Business:
Under new business, Karen Albert stated that abstracts from cancer-related meetings are not available in any database for searching. They are sometimes available on individual society web sites, such as ASCO. She reported that she had spoken to NLM about the problem, and they said that it might be possible to index these abstracts. Karen will put a message out on the listserv for comments and then forward that information to NLM. She also referred to the Journal of the National Cancer Institute publication by Oxford Press and the ensuing costs to libraries. She will contact MLA about this and follow up as needed.

Kathryn Hoffman asked if the Cancer Section members had participated in the benchmarking study for Hospital Libraries. Karen Albert reported that NCCN also has a benchmarking project, which she will investigate at the Fox Chase NCCN (National Community Cancer Network) office. Kathryn encouraged all section members to participate in the current benchmarking project of MLA.

Special thanks were given to Gerald (Jerry) Perry for attending the section business meeting as a representative of the MLA Board.

The meeting was adjourned at 2:30.

Respectfully submitted by:
Sue Felber
Medical Library
H. Lee Moffitt Cancer Center & Research Institute
Tampa, FL 33612

MLA 2003: Mentoring--Sharing Experiences for Professional Growth

Mentoring has become a national movement in business and industry as organizations strive to insure recruitment, retention and productivity of talented employees. Librarians who have traditionally sought talented and respected colleagues to share opinions and experiences in an informal manner are experiencing the need to explore more formal approaches to mentoring as we continue to recruit new members to our profession.

At the upcoming MLA Annual Meeting in San Diego, there will be a three-hour program on Wednesday, May 7 from 9am to 12 Noon, where members can learn about and discuss how to further develop, implement and maintain mentoring activities in their organization. The committee responsible for planning this program is the first to be composed of members from both Section Council (Stephen Greenberg, Jett McCann, Tovah Reis) and Chapter Council (Irene Lovas, Paula Raimondo, Debbie Sibley).

Consultant Karen Garman, Ed.D., who spoke at the November 2001 joint meeting of the Association of Academic Health Sciences Librarians (AAHSL) and the Association of Medical Colleges (AAMC), will set the stage for the program by providing an overview of mentoring. Dr. Garman is a nationally recognized speaker and consultant who specializes in the fields of mentoring, health care education, leadership and performance.

To share some of their unique experiences of professional growth, a distinguished panel of health sciences librarians including Sue Trombley, from the Arizona Health Sciences Library in Tucson, Ruth Holst, currently the associate director, NN/LM Greater Midwest Region, and Rick Forsman, director of the Denison Memorial Library at the University of Colorado Health Sciences Center will bring their perspectives of mentoring to the discussion. Sue is a recent graduate, Ruth is at mid-career and a former hospital librarian who has been and has mentored, and Rick is a “senior” librarian who has mentored librarians throughout his career.

A Town Meeting will cap off the morning. This will be the time for everyone to express opinions, to offer ideas and thoughts, and to ask any questions about mentoring. It will be an opportunity for MLA members to hear about the mentoring activities of MLA, its Sections and Chapters, and other professional associations and organizations. The Town Meeting will be the place to continue planning mentoring initiatives for our professional organization.

Before the Annual Meeting, there will be opportunities for you to assist the Committee in planning the Town Meeting. A bibliography of mentoring resources will be posted on MLANet. There will be a place on MLANet to post suggestions, comments and questions to be addressed at the Town Meeting. You also can email any ideas or questions to either Irene Lovas (email: Irene.Lovas@cshs.org) or Tovah Reis (Tovah_Reis@brown.edu). Please take this opportunity to participate as the MLA membership continues to develop and implement mentoring activities for future health sciences librarians.

Submitted by: Irene Lovas and Tovah Reis, Co-Chairs, MLA Joint Section/Chapter Councils Committee for MLA 2003
MEMBER UPDATES & ACCOMPLISHMENTS

Orick Awarded 2002 Hospital Librarian of the Year Award

The Hospital Library Committee awarded the Southern Chapter, Medical Library Association, Hospital Librarian of the Year 2002 to Jan Orick, Director of the Biomedical Library at St. Jude Children's Research Hospital, Memphis, TN at their annual meeting in October 2002.

Jan was nominated by her colleagues, friends and co-workers. Everyone commented on Jan's enthusiasm, generosity and innovative spirit in supporting patrons, her institution and other librarians. Jan has served as the THeSLA (the Tennessee Health Science Libraries Association) Vice-President and current President, and on numerous committees in service to the Southern Chapter/MLA. Ms. Orick is a Senior Member of the Academy of Health Information Professionals, MLA, and she is the Membership Chair for the Cancer Section. She is a contributing author for the chapter, "Locating and evaluating medical information on the World Wide Web" in Steen and Mirro's Childhood Cancer: A Handbook from St. Jude Children's Research Hospital, 2000. Ms. Orick presented a poster at the October 2002 Nashville SC/MLA meeting with Brenda Green, entitled, "Show me the money: locating resources for HIV/AIDS education funding." During the Hospital Library Luncheon of the same meeting, Jan joined the technology round robin to give a summary of the results on the use of Ariel by Southern Chapter hospital libraries.

Sue Felber was the 2001 Hospital Librarian of the Year for the Southern Chapter, MLA. Sue Felber is Coordinator of the Medical Library, H. Lee Moffitt Cancer Center & Research Institute in Tampa, FL. She is a Distinguished Member of the Academy of Health Information Professionals. Sue is currently Secretary for the Cancer Section of MLA, and serves on the Publication Committee of the Hospital Library Section, MLA as well as the Professional Development Committee, Southern Chapter/MLA. She presented a poster on "Keyword Indexing: Adding Value to the Moffitt Cancer Network (MCN) Web-based Education" at MLA in May and at Southern Chapter, MLA in October. She also presented a paper titled "Disseminating Library Instruction to the Desktop via the Web."

Vugrin Wins Grand Prize in AAMC Reporter’s 2002-2003 Photo Competition

The AAMC Reporter's September issue published the Grand Prize photo of their 5th annual photo competition. The theme was "A day in the life of a medical student." The image shows medical students engaged in research and surrounded by "too much information and too little time".

Grand Prize Winner:
Photographer: Margaret Vugrin M.S.L.S, AHIP collaborated with Jack Raines, M.A.T., M.L.I.S., AHIP on the winning image, which Jack will be using for outreach exhibits. Margaret is a Reference Librarian and Jack is the Senior Associate Director of Extramural Services at Texas Tech Health Sciences Center, Preston Smith Library, Lubbock, TX.

Link to the online image:
http://www.aamc.org/newsroom-reporter/sept02/dayinthelife.htm

"A Day in the Life of a Medical Student"


**Valerie G. Rankow, MLS**  
*Professional Information Services, Research, Writing & Consultation*

Valerie G. Rankow is a professional librarian with more than 30 years experience. She is presently the Library Director at Brookhaven Memorial Hospital Medical Center and, in addition, she operates a private information consulting business.

Rankow developed the following selective list of resources for conventional and complementary/alternative information about breast cancer, which was revised October 9, 2002.

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### Breast Cancer Information

- **American Cancer Society**  
  Includes Treatment Decision Tools and Breast Cancer Profiler for personalized information  

- **Breast Cancer Facts - University of Arizona**  
  [http://www.azcc.arizona.edu/prevent/Breast-cancer01.htm](http://www.azcc.arizona.edu/prevent/Breast-cancer01.htm)

- **Breast Cancer Info - A Service of the Susan G. Komen Breast Cancer Foundation and Breast Health: Everything You Need to Know About Breast Health & Breast Cancer**  

- **Breast Cancer Information Center: The Feminist Majority Foundation**  
  [http://www.feminist.org/other/bc/bchome.html](http://www.feminist.org/other/bc/bchome.html)

- **Breast Cancer Lighthouse**  

- **Breast Cancer Net**  
  Up-to-date news items and information  
  [http://www.breastcancer.net/](http://www.breastcancer.net/)

- **Breast Cancer.org - Breast Cancer Information**  

- **Breast Cancer PDQ® National Cancer Institute - Treatment Information for Health Professionals**  

- **Breast Cancer PDQ® National Cancer Institute - Treatment Information for Patients**  

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**Breast Cancer Research Semipostal**  
US Postage stamp breast cancer research fundraiser  
[http://shop.usps.com](http://shop.usps.com)  
Select Stamps by Subject → Social Awareness


**Breast Cancer Round Table**  
[http://www.seas.gwu.edu/student/llooms/MGT243/bcr.html](http://www.seas.gwu.edu/student/llooms/MGT243/bcr.html)

**Breast Cancer: Screening and Testing**  

**Breast Cancer: Steps to Finding Breast Lumps Early**  
AAFP Family Health Facts Doctor [English & Spanish]  

**Breast Health / Breast Cancer Glossary**  

**Breast Reconstruction**  
[http://www3.mdanderson.org/DEPARTMENTS/plastic/ptbreast.htm](http://www3.mdanderson.org/DEPARTMENTS/plastic/ptbreast.htm)

**Breast Reconstruction: A Review of the Research and Patient and Professional Resources**  

**Breast Reconstruction After Mastectomy - ACS**  
[http://www.cancer.org/docroot/crt/content/crt_2_6x_breast_reconstruction_after_mastectomy_5.asp](http://www.cancer.org/docroot/crt/content/crt_2_6x_breast_reconstruction_after_mastectomy_5.asp)

**Brigham & Women's Hospital**  
Breast Disease: Guide to Prevention, Diagnosis and Treatment  

**Cancer Guide: Steve Dunn's Cancer Guide**  
[http://cancerguide.org/](http://cancerguide.org/)

**Cancer Network** (Free registration required)  
[http://www.cancernetwork.com](http://www.cancernetwork.com)  
Select Breast Cancer from drop down menu

**CANSEARCH NCCS (National Coalition for Cancer Survivorship)**  
Resources by and for patients, in English and Spanish  
[http://www.canceradvocacy.org](http://www.canceradvocacy.org)

**CDC | The National Breast and Cervical Cancer Early Detection Program**  

**Columbia Presbyterian Medical Center - WAR**  
Women at Risk Breast Cancer Program at Columbia Presbyterian  
[http://breastmd.org/war.html](http://breastmd.org/war.html)

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Columbia-Presbyterian Medical Center - WAR Resource Library
Up-to-date bibliography of books and pamphlets for patient education; includes conventional and complementary therapies
http://breastmd.org/war_sup_resource.html

Estrogen Plus Progestin Study Stopped, NHLBI

FORCE: Facing Our Risk of Breast Cancer Empowered
Resources -- Hereditary Cancer, Genetic Counseling, BRCA Tests, Support Reducing Your Risk of Breast & Ovarian Cancer
http://www.facingourrisk.org/resources.php

Genetic Testing for BRCA1 & BRCA2: It's Your Choice
National Cancer Institute Fact Sheet
http://cis.nci.nih.gov/fact/3_62.htm

Genetic Testing for Breast Cancer Risk
http://rex.nci.nih.gov/NCI_PUB_INDEX/GENBRST/INDEX.HTM

Imaginis - Breast Health Specialists
http://imaginis.com/index.asp

Imaginis: Genetic Risk Factors for Breast Cancer

JAMA: Women's Health Information Center Journal Scan
Abstracts of current women's health information, including breast cancer research

Johns Hopkins Breast Center
http://www.hopkinsmedicine.org/breastcenter/

Long Island Breast Cancer Study Project
http://epi.grants.cancer.gov/LIBCSP/
http://nci.nih.gov/cancerinfo/LIBCSP (Digest and updates)

Male Breast Cancer (PDQ ®) Treatment - Health Professionals

Male Breast Cancer (PDQ ®) Treatment - Patients

MayoClinic.com Breast Cancer
http://www.mayoclinic.com/findinformation/conditioncenters/subcenters.cfm?objectid=00D5B62-89D1-1B37-8D7E80C8D77A0000

MayoClinic.com
Early-Stage Breast Cancer Health Decision Guide
http://www.mayoclinic.com/takecharge/healthdecisionguides/breastcancer/index.cfm?

M. D. Anderson Cancer Center
Nellie B. Connally Breast Center
http://www.mdanderson.org/Care_Centers/BreastCenter/

MEDLINEplus: Breast Cancer

MEDLINEplus: Breast Implants/Breast Reconstruction

Memorial Sloan-Kettering Cancer Center: Breast Cancer
http://www.mskcc.org/mskcc/html/293.cfm

Men with Breast Cancer
http://www.nabco.org/index.php/8

Michigan Breast Reconstruction Outcome Study (MBROS)
Consumer's Guide to Breast Reconstruction
http://www.surgery.med.umich.edu/breastrecon.htm

NABCO (National Alliance of Breast Cancer Organizations)
http://www.nabco.org

National Breast Cancer Awareness Month
(English and Spanish)
http://www.nbcam.org/

National Breast Cancer Centre (Sydney, Australia)
http://www.nbcc.org.au/

National Breast Cancer Coalition NBCC
http://www.natlbcc.org/

National Comprehensive Cancer Network
(in partnership with the American Cancer Society)
http://www.nccn.org/patient_gls/_english/_breast/index.htm

NHS (UK) National Electronic Library for Health Breast Cancer Website
Developed by the Cochrane Cancer Network
http://www.minervation.com/cancer/breast/professional/index.html

National Lymphedema Network (NLN)
http://www.lymphnet.org/

Oncolink: Breast Cancer
Searchable database of cancer research and information
http://www.oncolink.com/types/article.cfm?c=3&s=5&ss=33&id=8320

Online Management of Breast Diseases
TransMed Network
http://www.breastdiseases.com/index.htm

People Living With Cancer - Breast Cancer
http://www.peoplelivingwithcancer.org/plwc/MainConstructor/1,1744,21-008-00_12-001042-00_17-001029-00_04-001,00.html

Reconstructive Surgery of the Breast
(For Medical Professionals)
http://www.plasticsurgery.org/profinfo/breast.htm

SusanLoveMD.com
Website focuses on rapid advances and controversies in the treatment of breast cancer, maintained by author of Dr. Susan Love's Breast Book
http://www.susanlovedmd.com/

Y-ME National Breast Cancer Organization
(In English and Spanish) http://www.y-me.org/

Young Survival Coalition
Founded in 1998 by three young breast cancer survivors, all under the age of 35 at diagnosis, YSC is the only international, non-profit network of breast cancer survivors and supporters dedicated to the concerns and issues unique to young women with breast cancer.
http://www.youngsurvival.org/

YourSurgery.Com® Breast Surgery
http://www.yoursurgery.com/ProcedureDetails.cfm?BR=3&Proc=36

ALTERNATIVE/COMPLEMENTARY MEDICINE

For a clear, sensible overview of information on alternative therapies for cancer:
Lerner, Michael. Choices in healing: integrating the best of conventional and complementary approaches to cancer. MIT Press 1996, ISBN 0262621045 (pb); ISBN 0262121808 (cloth). Also available full-text, online, for FREE:
Choices in Healing by Michael Lerner
http://www.commonweal.org/choicescontents.html

American Cancer Society - Complementary and Alternative Methods
http://www.cancer.org/docroot/eto/eto_5.asp

British Columbia Cancer Agency Unconventional Cancer Therapies
http://www.bccancer.bc.ca/uct/

CancerGuide Material on Alternative Therapies
http://cancerguide.org/alternative.html

Duke University Medical Center and Cancer Center of Santa Barbara
http://cancer.duke.edu/pated/cam.asp

HealthWorld Online - Breast Cancer
http://www.healthy.net/clinic/dandc/breastca/index.asp

HealthWorld Online - Cancer Resource Center

M. D. Anderson Cancer Center / University of Texas Complementary / Integrative Medicine Education Resources
http://www.mdanderson.org/departments/cimer/

National Cancer Institute: Complementary and Alternative Medicine
http://www.cancer.gov/cancerinfo/treatment/cam

http://nccam.nih.gov/


OTHER RESOURCES

Breast Cancer Discussion Mailing List:
To subscribe: Send a message to LISTSERV@MORGAN.UCS.MUN.CA
Leave the subject line blank, and set the first message line to:
subscribe BREAST-CANCERyour_first_nameyour_last_name

http://www.newsday.com/ny-canceronlongisland0728.htmlstory

You may also contact the following organizations directly through email:
Blood & Marrow Transplant Newsletter: help@bmtnews.org
National Alliance of Breast Cancer Organizations: NABCOinfo@aol.com
Y-ME National Breast Cancer Organization: help@y-me.org

HORMONE REPLACEMENT THERAPY UPDATES


Postmenopausal Hormone Use


Please note: All links work as of December 11, 2002

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DEALING WITH THE TOUGH QUESTIONS

Gail M. Rink  
Executive Director  
Hospice of Santa Barbara, Inc.  
Santa Barbara, California

Information is emotional. Simple information – telephone numbers, addresses, recipes, fiction, sports articles, etc. – makes us feel secure, happy, and maybe, enlightened. Complex information – research for a dissertation, unfamiliar terminology, statistical data, etc. – makes us feel confused, frightened, and possibly, informed.

When we seek information about disease, treatment options and prognosis, the information is definitely emotional! We can assume that no one is immune from having feelings about life altering illness, invasive treatments, and precarious life expectancy. And, we can certainly expect to have an emotional response if the information is about a terminal illness with a limited prognosis. When the information, simple or complex, indicates death is the outcome, we have an emotional response.

Death is a main event. Each of us will die; the people we love will die. Death is a strong motivating force in our lives and its different aspects affect us differently.

Emotionally, we feel something when someone walks up to us and asks, “Can you help me find some information about breast cancer? My sister has just been diagnosed and I want to know what to expect so I can help her.”

Intellectually, we understand that we are not immortal. However, we also believe that if we live life correctly, we will live longer. The words correctly and healthy might be interchangeable here. Low fat diets, regular exercise, no smoking, moderate alcohol intake, low stress – are all acts of healthy living.

Politically, death influences public health policy. If health care is available to every American, there is more life for everyone. Vaccines, health education and low cost clinics insure longer life.

Chronologically, age influences our view of death. Age measures life lived and life left. When an elderly person dies, death has an acceptable explanation. “S/he lived a long, full life.” If a young adult dies, death is not comfortably explained. “S/he was taken in the prime of life.” And if a child dies, death is totally unexplainable. “I don’t understand why God let’s children die.”

Financially, death effects our monetary decisions and belief system. We Americans subconsciously believe that money buys more life. Money finances a better quality of life and a greater quantity of life.

Ethically, we are concerned about our ending. Thoughts on end of life care, DNR, and advanced directives bring out unique actions on our part.

After 22 years of hospice work, I am very familiar with emotional responses to mortality. Since the first hospice program began in Hartford, Connecticut in 1974, much has been accomplished in changing the American view of dying. New medical techniques, pharmaceuticals, hospice care in the home, television coverage of 9/11, research in thanatology and even Dr. Kevorkian have contributed to integrating the dying process into the living process. While Americans are more informed about death, we are – each of us – individually and solely responsible for our emotional responses to death. The response any one of us makes to the question, “Can you help me find some information about breast cancer?” is truly personal. Our feelings and beliefs about death, coupled with our life experiences, determine the style, tone and content of how we answer the question.

HELPFUL TIPS FOR WORKING WITH A CLIENT

- Work on coming to terms with your own feelings or fears about death.
- Become comfortable with gentle straightforward language.
- Respect individual and cultural differences.
- Be a genuine listener.
- Be aware of body language and non-verbal messages.
- Think as a librarian; act with insight into process (buffer resources and information with empathy).

FAVORITE BOOKS ABOUT DEATH AND GRIEF

- Albom, Mitch. Tuesdays With Morrie
- Attig, Thomas. The Heart of Grief: Death and the Search for Lasting Love
- Lewis, C.S. A Grief Observed
- Satterly, Lamont. If I Should Wake Before I Die
- White, E.B. Charlotte’s Web
- Elisabeth Kubler-Ross
- Earl G. Grollman

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End-of-life issues are an important aspect of the continuum of cancer care. Issues usually center on palliative care and hospice, which are different but closely related areas of care. Palliative care typically spans the period from acute treatment through the hospice experience. Hospice care is usually reserved for people in the last six months of life. The terms are frequently used interchangeably. Though the terms may vary in meaning, the objectives are the same. The goal of palliative care and hospice is to achieve the highest quality of life possible with focus on maintaining comfort and dignity at the end of life. Emphasis is placed not on curative treatment, but on the emotional, spiritual, psychological and physical comfort needs of the patient and the family.

As information professionals, we may be called upon to assist with information queries by both the health care professional and the consumer. Developing resources on advanced directives, palliative care and hospice are a useful addition to the cancer resource center.

**WEB SITES**

**Hospice Net**
Provides guides to issues and concerns that arise from life threatening illness. Includes information for caretakers, families and the dying.
http://www.hospicenet.org/

**Hospice Web**
Site provides a lengthy list of related links arranged by national, state and topical headings. Includes information on hospice including a handy FAQ section.
http://www.hospiceweb.com/

**National Hospice and Palliative Care Organization**
A very proactive organization, the NHPCO site has current news and legislation issues. Provides reproducible guides on grief and bereavement topics. Maintains a searchable database for finding local hospice care programs. Some information is available in Spanish.
http://www.nhpcoco.org/

**BOOKS**

*Issues are discussed through personal stories.*

*Written by a hospice physician, this is a practical, thoughtfully constructed guide for the family and caregiver on the hospice process.*

*A very nice guide on features of a culture that influence health care for that ethnic group. Includes death rituals. Arranged alphabetically by ethnic group.*

*This reference-style book for the consumer contains statistics, information on living wills and advanced directives, symptom management and other end-of-life issues.*

*Written by a well-known patients' rights advocate, the book covers all aspects of planning, understanding the last stages of life and communicating to health professionals and family.*

*Thoroughly discusses the topic with excellent resource for the patient and caregiver.*

*A practical, concise handbook with symptom management for the health professional, although some sections are readable by the educated public and provide suggestions and information that could be useful to them.*

Professional textbook has chapters covering numerous aspects of palliative care including ethics, symptom management, pain measurement, and psychosocial elements.


Text defines the nursing role of palliative care. Chapters include pain assessment, symptom management for quality of life and psychosocial support for both family and patient.


A textbook approach to transcultural issues in health care. Each ethnic group is discussed separately including death rituals.

VIDEOS


Suitable video for healthcare professionals and caregivers on end-of-life issues.

Quality of time: an introduction to hospice. Kaiser Permanente, 1992

Designed for the patient and family member, the video reviews the hospice program process.

LITERATURE REVIEW

This is a selected list of articles reviewing the issues of palliative and hospice care for the cancer patient and family unit.


Reviews pharmacists' responsibilities concerning the care of patients who might be nearing the end of life.


Article deals with quality of life issues faced by patients and the impact prevailing payment structures and medical system imposes.


Reviews current guidelines and standards. Discusses developing a training program for hospice nursing.


Article on palliative care includes tips and interview questions that doctors and nurses can use with their patients.


Very good discussion on symptoms, other than pain, that can contribute to suffering near the end of life, including management strategies.


Article for the family or caregivers of a cancer patient focusing on the goals and benefits of palliative care. Describes difference and similarities of palliative and hospice care.


Emphasis on the quality of life indicators for the dying and a tool for evaluation.
CANCER LIBRARIANS SECTION OFFICERS 2002/2003

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