



PARTNERS *for*
—•—
UNDERSTANDING PAIN

TOOL KIT

PAIN AWARENESS IS IMPORTANT TO NURSES
(PAIN) CAMPAIGN

September 2003



PARTNERS *for*
UNDERSTANDING PAIN

Table of Contents

	Page
Partners for Understanding Pain Mission	3
Partner List	4
Key Messages	7
<i>Pain Is Important to Nurses</i> Activity Suggestions	8
Developing a Grassroots Community Plan	9
Decade of Pain Control and Research	12
Pain Fact Sheet	13
Partners for Understanding Pain Survey Results	16
New Release	21
Radio Release	22
Let Your Voice be Heard	23
Resources for Nurses and People with Pain	26
Quality of Life Functional Pain Scale	147
Partners for Understanding Pain Logo	(on CD)
Partners for Understanding Pain Poster	(on CD)



PARTNERS FOR UNDERSTANDING PAIN MISSION

- Partners for Understanding Pain is a consortium of organizations that touch the lives of people with chronic, acute, and cancer pain.
- The partnership, spearheaded by the American Chronic Pain Association, will strive to create greater understanding among health care professionals, individuals and families who are struggling with pain management, the business community, legislators, and the general public that pain is a serious public health issue.
- Through its members, each of whom brings its own perspective to the dialogue, Partners for Understanding Pain represents a comprehensive network of resources and knowledge about issues in pain management.
- Partners for Understanding Pain is dedicated to building the understanding and support that can help people with chronic, acute and cancer pain lead better lives. Call 1-800-533-2075 (after July 1, 2002) or 1-800-533-3231 or visit www.theacpa.org for more information.



PARTNERS *for*
UNDERSTANDING PAIN

PARTNERS LIST

AMERICAN ACADEMY OF NURSE PRACTITIONERS

AMERICAN ACADEMY OF PAIN MANAGEMENT

AMERICAN ACADEMY OF PAIN MEDICINE

AMERICAN ACADEMY OF PHYSICAL MEDICINE AND REHABILITATION

AMERICAN ALLIANCE OF CANCER PAIN INITIATIVES

AMERICAN ASSOCIATION OF REHABILITATION NURSES

AMERICAN BACK SOCIETY

AMERICAN CANCER SOCIETY

AMERICAN CHRONIC PAIN ASSOCIATION

AMERICAN NURSES ASSOCIATION

AMERICAN PAIN FOUNDATION

AMERICAN PAIN SOCIETY

AMERICAN PHARMACISTS ASSOCIATION

AMERICAN PUBLIC HEALTH ASSOCIATION

AMERICAN RSDHOPE GROUP

AMERICAN SLEEP APNEA ASSOCIATION

AMERICAN SOCIETY OF PAIN MANAGEMENT NURSES

AMERICAN SOCIETY OF PERIANESTHESIA NURSES

ASSOCIATION OF REPETTIVE MOTION SYNDROMES

ARTHRITIS FOUNDATION

BAYLOR COLLEGE OF MEDICINE:
DEPARTMENT OF PHYSICAL MEDICINE & REHABILITATION.

CENTER FOR CANCER PAIN RESEARCH AT JOHNS HOPKINS

CHRONIC FATIGUE SYNDROME AND IMMUNE DYSFUNCTION SYNDROME (CFIDS) ASSOCIATION OF
AMERICA

CIRCLE OF FRIENDS WITH ARACHNOIDITIS

COVENANT HEALTH SYSTEM, COVENANT MEDICAL CENTER & COVENANT LAKESIDE

DEPARTMENT OF VETERAN AFFAIRS MEDICAL CENTER, HOUSTON, TX

ENDOMETRIOSIS RESEARCH CENTER

FAMILY CAREGIVERS ALLIANCE

FOR GRACE

INSTITUTE FOR HEALTH AND PRODUCTIVITY MANAGEMENT

INTERCULTURAL CANCER COUNCIL

INTERNATIONAL ENDOMETRIOSIS ASSOCIATION

INTERNATIONAL POLIO NETWORK

INTERSTITIAL CYSTITIS ASSOCIATION

LUPUS FOUNDATION OF AMERICA

MEN'S HEALTH NETWORK

NATIONAL ASSOCIATION FOR THE ADVANCEMENT OF COLORED PEOPLE

NATIONAL ASSOCIATION OF SOCIAL WORKERS

NATIONAL BLACK WOMEN'S HEALTH PROJECT

NATIONAL CHRONIC PAIN OUTREACH

NATIONAL CHRONIC PAIN SOCIETY

NATIONAL COMMITTEE ON THE TREATMENT OF INTRACTABLE PAIN

NATIONAL CONSUMER LEAGUE
NATIONAL FIBROMYALGIA ASSOCIATION
NATIONAL FIBROMYALGIA PARTNERSHIP
NATIONAL HEADACHE FOUNDATION
NATIONAL PAIN FOUNDATION
NATIONAL URBAN LEAGUE
NATIONAL VULVODYNIA ASSOCIATION
NATIONAL WOMEN'S HEALTH RESOURCE
NATIVE AMERICAN CANCER RESEARCH
PAIN POLICY FOUNDATION, INC.
PAIN & POLICY STUDIES GROUP: UNIVERSITY OF WISCONSIN
POST-POLIO HEALTH INTERNATIONAL
PROGRESS ON PAIN
REFLEX SYMPATHETIC DYSTROPHY SYNDROME (RSDS) ASSOCIATION OF AMERICA
SICKLE CELL DISEASE ASSOCIATION
SOUTHERN CALIFORNIA CANCER PAIN INITIATIVE
SIDNEY KIMMEL CANCER CENTER AT JOHN HOPKINS
THE NEUROPATHY ASSOCIATION
THE TMJ ASSOCIATION
TRIGEMINAL NEURALGIA ASSOCIATION
TRIUMPH OVER PAIN FOUNDATION
UNIVERSITY OF FLORIDA COMPREHENSIVE CENTER FOR PAIN
VZV RESEARCH FOUNDATION



KEY MESSAGES

- **Pain is a major health issue.** Unmanaged pain can slow the rate of recovery for surgical patients and affect the quality of outcomes. Cancer patients who experience breakthrough pain are hospitalized and visit the emergency room more often than patients whose pain is under control. Pain is the number-one cause of adult disability in the United States and affects one in three people or about 50 million Americans. According to an omnibus survey of 1,000 Americans conducted for the Partners for Understanding Pain, 34 percent of respondents said they currently live with ongoing pain. In spite of its pervasiveness, few physicians receive more than a few hours of formal training on pain management
- **Pain is a major economic issue.** According to the National Institute for Occupational Safety and Health, pain costs \$100 billion annually in lost workdays, medical expenses, and other benefit costs. Skyrocketing health care costs leave some, especially senior citizens, minorities, and the urban and rural poor, unable to get treatment that can help them manage their pain.
- **Pain is a major social issue.** Long-term, unmanaged pain can cause people to withdraw from family and friends and leave them unable to care for children, hold steady jobs, and at times even face a personal future. Pain has an impact on the fabric of society well beyond the individual, effecting his or her spouse or partner, children, family, and community.
- **Nurses care about pain** and want to help bring attention to the need for ongoing assessment and proper pain management in all areas of the health care and social system.



Partners for Understanding Pain
presents
Pain Awareness Is Important to Nurses
Nurses' Pain Awareness Events
September 2003

Nurses are the front line in pain management. No one else on the treatment team has more one-to-one contact with people experiencing pain.

The campaign is part of September Pain Awareness Month activities developed by Partners for Understanding Pain and its members the American Academy of Nurse Practitioners, the American Association of Rehabilitation Nurses, American Nurses Association, American Society of Pain Management Nurses, and the American Society of Perianesthesia Nurses.

By sponsoring a Pain Awareness Day within your clinical setting, you can make a difference in the assessment, treatment, and long-term management of pain. The goals of the Nurses' PAIN campaign are to:

- Create a focus on pain within a range of clinical settings;
- Engage the "front line" of patient care in a more informed and sensitive response to pain;
- Provide a catalog of resources to nurses in a wide range of settings for their use in helping patients and the public;
- Generate community awareness through buttons and posters to be displayed in the facility during September.

Suggested events:

- Luncheon conference with expert speaker in pain management
- Lecture series on assessment and treatment of pain throughout the day
- Cafeteria table with petitions, materials, and resource lists for the public
- Health fair of community resources for people with pain
- Distribution of buttons to all staff members attached to flyer about pain assessment and management

For more information, contact the American Chronic Pain Association at 800-533-3231 or by email at acpa@pacbell.net.



Action for Awareness of Chronic, Acute, and Cancer Pain

Developing the Foundation for a Grassroots Community Public Relations Plan

SITUATION

Pain can touch all of us. It is estimated that one in three people experience some type of ongoing, chronic pain. Chronic, cancer and acute pain are often under-treated leading to increased use of health care resources and needless suffering. The impact of pain on our economy, our society, and healthcare is significant.

Yet there is still apathy and a lack of understanding about pain. Now, in the “Decade of Pain Control and Research,” the American Chronic Pain Association (ACPA) is bringing together Partners for Understanding Pain, a consortium of more than 60 organizations to raise awareness about chronic, acute, and cancer pain through grassroots community outreach and a national media relations campaign.

The most important resource of our partnership is each organization’s ability to spread the word about chronic, acute, and cancer pain. To maximize your involvement in the partnership, the ACPA has developed the following document to suggest ways to raise awareness in your local community.

We welcome you to take these suggestions and customize them to align with your own organization’s mission. **Together, we can saturate our local communities to bring pain to the forefront of public health issues.**

COMMUNITY OUTREACH IDEAS

➤ Web site development

Developing a pain awareness education section of your organization’s Web site will spread the word about pain through education. Suggested items for the Web site:

- ◇ Partners for Understanding Pain logo and link on homepage.
- ◇ Fact sheet about the three types of pain.
- ◇ Facts sheets about the Partners for Understanding Pain.
- ◇ Links to Partner organizations and their resources.
- ◇ Facts about how pain touches your organization.
- ◇ Information on ACPA, its materials and resources, including how to tap into them.
- ◇ Local community resource guide for people who have pain issues.
- ◇ If relevant to your organization, success stories about people who have dealt effectively with pain.

➤ **Cultivate community partnerships with local businesses and organizations**

Partnering with local businesses and organizations that may have a health-related mission will provide a key outlet to spread the word about pain management and to continue to build a network of partners. (Check the Partners list to identify any in your community.)

Partnership ideas:

- ◇ Ask organizations to post and distribute materials about pain, resources, and information about the Partners for Understanding Pain program.
- ◇ Co-sponsor a community event, re: walk to raise awareness for the importance of pain management.
- ◇ Set up a booth or pass out information about pain at already established community events.
- ◇ Set up appointments with local legislators to educate them about pain and how it's a major health issue that needs attention.
- ◇ Establish or re-establish connections with local hospitals to hold support meetings for people with pain. Invite hospital doctors or health care professionals to talk about pain management.

Suggested places to promote pain and Partnership message materials:

- ◇ Drug stores
- ◇ Hospitals/doctors office
- ◇ Local chapters of health-related organizations; health fairs
- ◇ Health insurers
- ◇ Fitness centers/health-related stores
- ◇ Churches
- ◇ Libraries
- ◇ Senior centers

➤ **Join with local Partners, such as chapters of the Arthritis Foundation, Lupus Foundation of America, National Consumer League**

Contact local health-related organizations to promote the partnership and identify possible collaboration areas including:

- ◇ Offering a speaker to talk about how pain touches those with heart disease, diabetes and cancer; make the information relevant to their organization.
- ◇ Asking organizations to identify success stories among their members.
- ◇ Asking organizations to display information about the Partners for Understanding Pain's resources and materials at community events and on their Web site.

➤ **Pain ambassadors volunteer program**

- ◇ Local university, school, and church groups often seek volunteer opportunities. Join with them to create a volunteer program for students. Volunteers may visit or help with activities of people with pain who may live alone, creating a support network. They also may work for the awareness campaign directly.

- **“Ask the doctor” about pain day**
 - ◇ Partner with local drug store, fitness, or health-related stores to sponsor a health care professional to be available to answer questions related to pain management for a day in the store.
- **Create a resource guide for people with pain in your community**
 - ◇ Creating a community resource guide for people who have chronic or cancer pain and their families can serve as an outlet to make people aware of the services in their community.

Suggested inclusions for the guide:

- ◇ Local pain doctors
 - ◇ Local physical therapy organizations
 - ◇ Local health food stores
 - ◇ Support groups
 - ◇ Local health-related organizations and programs
 - ◇ Financial advisors and assistance resources
 - ◇ Transportation resources for disabled
 - ◇ Home health services
 - ◇ Homemaking services
 - ◇ Meals on wheels
 - ◇ Senior centers
 - ◇ Recreational opportunities in the community that provide craft lessons and such
- **In-service staff trainings and ongoing pain education at local hospitals**
 - ◇ Partner with local hospitals and health care facilities to offer training on the intricacies of chronic and cancer pain to facilitate understanding among other health care professionals.
 - ◇ Partner with local hospitals to offer ongoing pain education outreach such as tabletop displays that offer facts about chronic and cancer pain.

If you have any questions, please call our office at 800-533-3231.



2001 TO 2010: THE DECADE OF PAIN CONTROL AND RESEARCH

Challenges and Opportunities



In passing HR 3244, Congress officially declared the ten calendar years beginning on January 1, 2001 to be the Decade of Pain Control and Research. President Clinton signed the bill into law in October, 2000. This is only the second named decade in our history, following the Decade of the Brain in the 1990s.

With this designation, brought about through the efforts of the American Academy of Pain Medicine, the American Headache Society, and the American Pain Society, it was hoped that public attention and funding for research would be focused on an under-recognized but very serious issue.

Yet, as we look ahead to the third year of the decade, we have barely begun.

- Multi-disciplinary pain management units face program-imperiling budget cuts as health care facilities struggle with declining revenues.
- Skyrocketing pharmaceutical costs leave some, especially seniors, without the means to acquire the medicines that can help them manage their pain.
- Abuse of medications by a small number of individuals has refueled fears about addiction and reawakened stigmas that keep many from even asking about pain management medicines.
- Underserved minorities continue to do without.

- And myths about pain and our potential for managing it prevail in the general population.

Partners for Understanding Pain was created to address these and other critical issues surrounding pain management today. Our hope and our mandate is to raise awareness about the sources of pain and the resources now available to people who suffer. Medical research has come far, but we still have far to go.

By joining together and giving a human face and voice to a problem we all share, we pledge to mobilize resources to fulfill the promise of the Decade of Pain Control and Research.



PARTNERS *for*
UNDERSTANDING PAIN

PAIN FACT SHEET

Pain touches each one of us at one time or another. Pain can begin for many different reasons. Yet as common as pain is, the medical community is just beginning to understand and better address the many forms of pain.

Partners for Understanding Pain developed this fact sheet to provide information and to distinguish among the three types of pain—chronic, acute, and cancer pain.

Acute pain has a distinct beginning and end and is the result of illness or injury. This type of pain usually can be largely relieved with appropriate treatment, as can cancer pain. It is important that the pain be taken seriously and managed as part of sound patient care.

Currently there is no cure for chronic pain and, as a condition that can affect individuals life long, it also needs to be taken seriously. A multidisciplinary treatment approach can help people with chronic pain regain control of their lives and reduce their sense of suffering.

CHRONIC PAIN FACTS

Key Facts:

- Chronic pain lasts. Pain is considered chronic when it continues beyond the usual recovery period for an injury or an illness. It may be continuous or come and go.
- Chronic pain, sometimes called persistent pain, can be very stressful for both the body and the soul and requires careful, ongoing attention to be appropriately treated.
- Chronic pain is often intractable, as the cause of pain cannot be removed or treated.
- Chronic pain is the number one cause of adult disability in the United States.
- Chronic pain can touch nearly every part of a person's daily life. It also has an impact on the family and, because of its economic and social consequences, it affects us all.
- Chronic pain can be a source of frustration for the health care professionals who seek to provide care and assistance.

Incidence:

- The American Chronic Pain Association (ACPA) estimates that one in three Americans (approximately 50 million people) suffers from some type of chronic pain.

Causes:

- Lower back problems, arthritis, cancer, RSDS, repetitive stress injuries, shingles, headaches, and fibromyalgia are the most common sources of chronic pain. Others include diabetic neuropathy, phantom limb sensation, and other neurological conditions.

ACUTE PAIN FACTS

Key Facts:

- Acute pain may be mild and last just a moment. It also can be severe and last for weeks or months, as does pain from a burn, pulled muscle, or broken bone.
- Acute pain has a distinct beginning and end. The cause of acute pain is known and, as you heal, the pain will lessen and finally go away.
- Acute pain usually starts suddenly, may be sharp, and often triggers visible bodily reactions such as sweating, an elevated blood pressure, and more. Acute pain is generally a signal of rapid-onset injury to the body and it resolves when pain relief is given or the injury is treated.
- Pain should be considered the fifth vital sign, along with respiration, pulse, blood pressure, and core temperature.
- Most of the time medication and other treatment can greatly relieve acute pain. Pain management is an important part of effective total care.

Incidence:

- Muscle pain, one of the most common types of acute pain, affects 53 percent of Americans.
- Lower back pain is the most common form of acute pain and is the fifth most common cause for all physician visits. It is responsible for direct health care expenditures of more than \$20 billion annually.

Causes:

- Acute pain is triggered by tissue damage such as a skin burn, muscle pain, or a broken bone. It's the type of pain that generally accompanies an illness, an injury, or surgery.
- Acute pain can manifest in just about any part of the body.

CANCER PAIN FACTS

Key Facts:

- Not everyone who has cancer experiences pain; those who do may not have it all the time.
- Ongoing cancer pain can be successfully treated in about 95 percent of people with cancer with the drug and non-drug therapies that are currently available.
- Along with ongoing cancer pain, sometimes people have acute flares of pain when not all pain is controlled by the medication or therapy. This pain, usually called breakthrough pain, can also be controlled by additional medications.

- Cancer patients often downplay their pain to doctors for fear that their pain means that their cancer is getting worse or that they will be thought to be complainers.
- In almost every aspect of cancer treatment—surgery, chemotherapy or radiation—cancer patients follow the lead of their doctors. But when it comes to pain, patients need to assert themselves and be open about the degree of pain they are experiencing.

Incidence:

- Approximately 30 to 40 percent of Americans diagnosed with cancer experience moderate to severe pain, with 90 percent of people who have a more advanced diagnosis of cancer experiencing significant amount of pain.
- Sixty to 80 percent of all cancer patients with bone metastases feel pain.

Causes:

- Most cancer pain is caused by the effects of cancer itself, the side effects of treatment, compression on bones, nerves or body organs, poor blood circulation, blockage of an organ, metastasis, infection, or inflammation.



PAIN AWARENESS SURVEY

Partners for Understanding Pain commissioned a survey to identify current levels of awareness and understanding of pain and pain management issues among the general population. The survey was conducted in June 2002 and polled 1000 adult Americans. Results are representative of and projectable to the US adult population.

Here are highlights of the findings.

What is the number one reason for going to the doctor in the US?

	All	Male/Female	Metro/Non-Metro	White	Black	Hispanic
Pain	27%	24%/30%	27%/26%	27%	28%	26%
Cold or flu	35%	38%/32%	36%/33%	36%	25%	43%
Injury	17%	17%/18%	17%/18%	16%	26%	13%
Check ups	16%	15%/16%	16%/15%	16%	15%	13%
Headache	3%	3%/2%	2%/3%	2%	7%	3%
Don't Know/No Answer	2%	3%/2%	1%/5%	2%	0%	1%

One-third of Americans (35%) think that the number one reason people go to the doctor is for the cold or flu. Pain (27%) is the next most commonly cited reason for a doctor visit, followed by injury (17%) and checkups (16%).

What is the number one cause of disability in the United States?

	All	Male/Female	Metro/Non-Metro	White	Black	Hispanic
Chronic pain	36%	40%/32%	37%/35%	39%	17%	44%
Stroke	16%	15%/16%	15%/16%	14%	26%	14%
Hearing loss	1%	1%/1%	1%/2%	1%	1%	1%
Cancer	19%	16%/23%	18%/22%	18%	28%	20%
Heart attack	24%	23%/24%	25%/20%	23%	27%	18%
Don't Know/No Answer	4%	4%/4%	4%/5%	5%	0%	2%

Chronic pain is the most commonly cited cause of disability in the US by 36% of the respondents. Fewer think heart attack (24%), cancer (19%) or stroke (16%) is the number one cause of disability in this country.

Do you agree: Pain is a normal part of many injuries and illnesses and there is not much that can be done to treat it.

	All	Male/Female	Metro/Non-Metro	White	Black	Hispanic
Agree strongly	12%	12%/13%	13%/11%	12%	18%	12%
Agree	30%	32%/28%	29%/31%	29%	37%	34%
Neither agree nor disagree	8%	9%/7%	8%/9%	9%	6%	5%
Disagree	35%	32%/38%	35%/35%	36%	26%	30%
Disagree strongly	13%	14%/12%	14%/12%	13%	13%	20%
Don't Know/No Answer	1%	1%/2%	1%/2%	1%	0%	0%

About half of the respondents disagreed with this statement (48%) while a similar proportion (42%) agreed.

Do you feel your physician is equipped with the knowledge to diagnose and treat pain problems?

DIAGNOSE	All	Male/Female	Metro/Non-Metro	White	Black	Hispanic
Yes	79%	78%/79%	78%/81%	80%	76%	67%
No	16%	16%/16%	16%/15%	14%	22%	28%
Don't Know/No Answer	5%	6%/5%	6%/4%	6%	3%	5%

TREAT	All	Male/Female	Metro/Non-Metro	White	Black	Hispanic
Yes	83%	81%/84%	82%/85%	82%	92%	75%
No	13%	13%/12%	13%/11%	13%	6%	19%
Don't Know/No Answer	5%	6%/4%	5%/4%	5%	1%	6%

Respondents are quite confident that their primary care physician has the knowledge to diagnose (79%) and treat (83%) pain problems.

How likely do you think it is that treating pain with strong medicines is likely to result in patients becoming addicted to the drugs?

	All	Male/Female	Metro/Non-Metro	White	Black	Hispanic
Very likely	29%	26%/31%	28%/30%	28%	33%	28%
Somewhat likely	49%	51%/48%	49%/49%	49%	55%	44%
Not too likely	17%	18%/16%	17%/15%	18%	8%	24%
Not at all likely	3%	3%/3%	3%/3%	3%	4%	4%
Don't Know/No Answer	2%	2%/3%	1%/3%	2%	0%	1%

Most respondents (78%) think there is a very (29%) or somewhat (49%) likely possibility that treating pain with strong medicine will result in the patient becoming addicted. Just one in five thinks addiction is not too or not at all likely if pain is treated with strong medicine.

What is the typical profile of someone who lives with ongoing pain?

	All	Male/Female	Metro/Non-Metro	White	Black	Hispanic
Adults over the age of 65	43%	45%/42%	45%/38%	44%	38%	29%
Adults aged 25-64	30%	30%/31%	30%/32%	31%	25%	40%
Adults aged 18 to 24	2%	2%/1%	1%/2%	1%	4%	0%
Teenagers	Less than 1%	1%/less than 1%	Less than 1%/1%	Less than 1%	1%	0%
Children	Less than 1%	0%/ less than 1%	0%/1%	Less than 1%	0%	0%
All of the above	23%	21%/24%	22%/24%	22%	31%	30%
None Of The Above	Less than 1%	Less than 1%/ Less than 1%	Less than 1%/0%	Less than 1%	0%	1%
Don't Know/No Answer	1%	1%/2%	1%/2%	1%	0%	0%

Most respondents think the typical profile of someone who lives with ongoing pain is:

An adult aged 65 or over (43%)

An adult aged 25-64 (30%)

Practically no respondents think the typical profile of a person living in pain is a teenager or young child (1%).

Do you agree: Some people exaggerate their pain to get pain killers or attention or to avoid work.

TO GET PAIN KILLERS	All	Male/Female	Metro/Non-Metro	White	Black	Hispanic
Strongly Agree	28%	27%/28%	29%/25%	28%	28%	36%
Agree	55%	56%/54%	55%/55%	55%	56%	51%
Neither agree nor disagree	5%	4%/7%	5%/5%	6%	2%	4%
Disagree	9%	12%/7%	9%/10%	9%	12%	9%
Strongly Disagree	1%	1%/2%	1%/1%	1%	1%	1%
Don't Know/No Answer	2%	1%/3%	1%/3%	2%	1%	0%

TO GET ATTENTION	All	Male/Female	Metro/Non-Metro	White	Black	Hispanic
Strongly Agree	28%	27%/29%	28%/28%	28%	27%	33%
Agree	58%	60%/56%	57%/59%	58%	57%	53%
Neither agree nor disagree	4%	3%/5%	4%/3%	5%	1%	1%
Disagree	9%	8%/9%	10%/6%	8%	13%	12%
Strongly Disagree	1%	Less than 1%/1%	1%/1%	1%	0%	1%
Don't Know/No Answer	1%	1%/1%	Less than 1%/2%	1%	1%	0%

TO AVOID WORK	All	Male/Female	Metro/Non-Metro	White	Black	Hispanic
Strongly Agree	28%	31%/26%	29%/27%	28%	32%	39%
Agree	55%	53%/57%	55%/57%	55%	57%	48%
Neither agree nor disagree	4%	5%/4%	5%/4%	5%	1%	4%
Disagree	9%	10%/9%	10%/8%	10%	8%	8%
Strongly Disagree	1%	Less than 1%/1%	Less than 1%/2%	1%	1%	1%
Don't Know/No Answer	2%	1%/2%	1%/2%	2%	0%	0%

A substantial majority of respondents agreed that some people have the tendency to exaggerate their pain to get attention (86%); avoid work (84%); get pain killers (83%).

The youngest respondents are much more likely to think people exaggerate pain to avoid work (91%) or get pain killers (90%) than are those aged 65 or over (80% and 78% respectively).

Do you currently live with ongoing pain?

	Male/Female	Metro/Non-Metro	White	Black	Hispanic
Yes	35%/34%	32%/41%	36%	31%	34%
No	65%/66%	68%/58%	64%	68%	66%

	All	Those over 65	Income under \$15k	Income over \$50k
Yes	34%	49%	46%	27%
No	65%	51%	53%	73%

One-third of the respondents said they currently live with ongoing pain. Those living with ongoing pain tend to be over 65 (49%); and have lower incomes or less education.



FOR IMMEDIATE RELEASE

CONTACT: YOUR CONTACT
YOUR ORGANIZATION
YOUR PHONE

PENNEY COWAN
AMERICAN CHRONIC PAIN ASSOC.
800-533-3231

NURSES CALL ATTENTION TO THE IMPACT OF PAIN

*Nursing Groups of Partners for Understanding Pain Mark
PAIN: Pain Awareness is Important to Nurses during
September Pain Awareness Month*

YOUR TOWN, State, September __, 2003— September has been declared Pain Awareness Month by the Partners for Understanding Pain, a consortium of more than 60 professional and consumer organizations that have an interest in pain. As part of this effort, nurses in **(your workplace)** are sponsoring **PAIN: Pain Awareness is Important to Nurses** to bring attention to the importance of appropriate pain management in the clinical setting.

Unmanaged pain can slow the rate of recovery for surgical patients and affect the quality of outcomes. Cancer patients who experience breakthrough pain are hospitalized and visit the emergency room more often than patients whose pain is under control. Costs associated with prolonged chronic pain total approximately \$100 billion a year. And nurses often find themselves on the front lines of the fight against pain. Through the grass roots **PAIN: Pain Awareness is Important to Nurses** campaign nurses hope to increase awareness and understanding among health care facilities' staff, patients, and the public about the complex issues of assessing and treating pain.

Add quote from your organization spokesperson here.

The campaign is part of September Pain Awareness Month activities developed by Partners for Understanding Pain and its members the American Academy of Nurse Practitioners, the American Association of Rehabilitation Nurses, American Nurses Association, American Society of Pain Management Nurses, and the American Society of Perianesthesia Nurses.

“Pain can touch any of us,” noted Penney Cowan, Executive director of the American Chronic Pain Association and convener of Partners for Understanding Pain. “It is the number one cause of adult disability in the United States, affecting one in three Americans, yet there is still apathy and a lack of understanding about pain.” Now, in the Decade of Pain Control and Research, Partners for Understanding Pain is dedicated to raising awareness about chronic, acute, and cancer pain through community outreach and a national media campaign. Partners’ goals also include building a more comprehensive network of knowledge and better utilizing existing resources about pain management among its members.

For more information about other activities of Partners for Understanding Pain, contact the American Chronic Pain Association at 800-533-3231 or by email at acpa@pacbell.net.

###



PARTNERS for
UNDERSTANDING PAIN

DRAFT SCRIPT

ANNOUNCER:

NURSES AT (FACILITY NAME) ARE WORKING TO BRING ATTENTION TO THE NEED FOR BETTER PAIN ASSESSMENT AND TREATMENT. THEIR EFFORTS ARE PART OF ACTIVITIES PLANNED BY PARTNERS FOR UNDERSTANDING PAIN, A CONSORTIUM OF MORE THAN 60 PROFESSIONAL AND CONSUMER ORGANIZATIONS THAT HAVE AN INTEREST IN PAIN AND ITS EFFECTS, FOR SEPTEMBER'S PAIN AWARENESS MONTH ACTIVITIES.

UNMANAGED PAIN CAN SLOW THE RATE OF RECOVERY FROM SURGERY. CANCER PATIENTS WITH UNMANAGED PAIN ARE HOSPITALIZED AND VISIT THE EMERGENCY ROOM MORE OFTEN THAN PATIENTS WHOSE PAIN IS UNDER CONTROL. AND COSTS ASSOCIATED WITH PROLONGED CHRONIC PAIN TOTAL APPROXIMATELY \$100 BILLION A YEAR. NURSES OFTEN FIND THEMSELVES ON THE FRONT LINES OF THE FIGHT AGAINST PAIN.

SOUNDBITE:

“PAIN IS A SERIOUS PUBLIC HEALTH AND ECONOMIC ISSUE THAT AFFECTS US ALL. BUT THERE IS A LACK OF UNDERSTANDING AMONG HEALTH CARE PROVIDERS AND CONSUMERS ALIKE. THE NURSING STAFF AT (YOUR FACILITY) IS CONDUCTING A PAIN AWARENESS DAY ON (DATE) TO FOCUS ON THE IMPORTANCE OF THE TREATMENT AND ASSESSMENT OF PAIN.”

ANNOUNCER:

TO LEARN MORE ABOUT PAIN AWARENESS DAY, CONTACT (YOUR NAME) AT (PHONE NUMBER) AND, FOR RESOURCES AND INFORMATION ABOUT PAIN, VISIT W-W-W-DOT-T-H-E-A-C-P-A-DOT-ORG. I'M _____ REPORTING.



**LET YOUR VOICE BE HEARD:
WRITING LETTERS TO MEMBERS OF CONGRESS AND GOVERNORS**

Together our voices are very strong! We invite you to join us in a letter-writing campaign to help ensure that September is recognized as pain awareness month, beginning with September 2003.

Our letters also can bring to the attention of our elected officials the enormous impact pain has in health care costs, economic productivity, and human suffering on the people they represent.

Sample letters and petitions follow. Please modify them to reflect your mission as appropriate.

Taking it the next level

Meeting with the elected official also can be helpful. Call his or her office to see when a convenient time might be to meet and discuss the issues your organization faces in the complex problem of pain

Your organization has a voice

Share this information with your members and ask them to write letters also. You may wish to post the letter and the tips below on your web site to encourage all who visit your web site to help bring the issue of pain to the forefront. To learn how to contact their congress and senators, they may log on to <http://www.visi.com/juan/congress/>

Tips on writing to policy makers

- Be sure to include your name and the organization that you are representing (use your letterhead, if possible)
- Get to the point immediately
- Keep it brief
- Remember that you are the expert on this topic
- Provide a follow up plan to contact them
- Make sure that you include a return address and a phone number where you can be reached in the signature

You also may develop an on-line petition to be signed in support of declaring September as Pain Awareness Month and Partners for Understanding Pain. Post our petition in your offices or agency and take copies to community days and other events. Good luck!

SAMPLE LETTER

(Date)

Name

Address

City, State Zip

Dear Senator or Governor (last name)

On behalf of _____ *Partner Group* _____ and Partners for Understanding Pain, I ask for your support in declaring September, 2003, and subsequent Septembers Pain Awareness Month.

Pain is a major health issue. It is the number-one cause of adult disability in the United States and affects one in three people or about 50 million Americans. According to an omnibus survey of 1,000 Americans conducted for the Partners for Understanding Pain, 34 percent of respondents said they currently live with ongoing pain. In spite of its pervasiveness, few physicians receive more than a few hours of formal training on pain management

Pain is a major economic issue. According to the National Institute for Occupational Safety and Health, pain costs \$100 billion annually in lost workdays, medical expenses, and other benefit costs. Skyrocketing health care costs leave some, especially senior citizens, minorities, and the urban and rural poor, unable to get treatment that can help them manage their pain.

Pain is a major social issue, with an impact well beyond the individual on his or her spouse or partner, children, family, and community.

For only the second time in history, the US Congress has declared a theme for a decade; we are now in the second year of the **Decade of Pain Control and Research**. In this context, Partners for Understanding Pain brings together more than 60 organizations to build understanding of chronic, acute, and cancer pain issues and the impact of pain today. For more information about Partners for Understanding Pain, call 1-800-533-3231 or visit www.theacpa.org.

WE ASK YOU TO SUPPORT OF OUR EFFORTS TO HAVE PAIN TAKEN SERIOUSLY BY HELPING US HAVE SEPTEMBER DECLARED PAIN AWARENESS MONTH. I WILL CALL YOUR OFFICE ON (DAY, DATE, TIME) TO ANSWER ANY QUESTIONS YOU MIGHT HAVE. I HOPE THAT WE CAN COUNT ON YOUR SUPPORT.

Thank you for your consideration to this very important issue.

Name

Organization

Address

Phone number

e-mail

SAMPLE PETITION

List names of members of congress/governor to whom the petition will be sent.

By our signatures on this petition, we urge you to take action to have September, 2003, and subsequent Septembers declared Pain Awareness Month. We believe that pain needs to be taken seriously for these reasons:

Pain is a major health issue. It is the number-one cause of adult disability in the United States and affects one in three people or about 50 million Americans. According to an omnibus survey of 1,000 Americans conducted for the Partners for Understanding Pain, 34 percent of respondents said they currently live with ongoing pain. In spite of its pervasiveness, few physicians receive more than a few hours of formal training on pain management

Pain is a major economic issue. According to the National Institute for Occupational Safety and Health, pain costs \$100 billion annually in lost workdays, medical expenses, and other benefit costs. Skyrocketing health care costs leave some, especially senior citizens, minorities, and the urban and rural poor, unable to get treatment that can help them manage their pain.

Pain is a major social issue, with an impact well beyond the individual on his or her spouse or partner, children, family, and community.

Signatures:

Name

Address

PAIN AWARENESS IS IMPORTANT TO NURSES
(PAIN)



PARTNERS *for*
—•—
UNDERSTANDING PAIN

RESOURCES

September 2003



PARTNERS *for*
UNDERSTANDING PAIN

Table of Contents

Partner Organization	Page
American Alliance of Cancer Pain Initiatives	28 -29
American Academy of Pain Management	30
American Academy of Pain Medicine	31- 32
American Academy of Physical Medicine and Rehabilitation	33
American Back Society	34
American Chronic Pain Association	35-39
American Pain Foundation	40-41
American Pain Society	42
American RSDSHope Group	43
American Rehabilitation Nurses	44
American Society of Perianesthesia Nurses	45 - 49
Chronic Fatigue	50
City of Hope Pain/Palliative Care Resource Center	51 - 124
Endometriosis Association, International	125 - 126
For Grace	127
National Pain Foundation	128
National Women's Health Resource Center	129
Interstitial Cystitis	130 - 131
Lupus Foundation of American	132
Men's Health Network	133
National Headache Foundation	134 - 139
National Urban League	140
National Vulvodynia Association	141
The Neuropathy Association	142
Post Polio Health International	143 - 4
Reflex Sympathetic Dystrophy Syndrome Association	145
Trigeminal Neuralgia Association	146



AMERICAN ALLIANCE OF CANCER PAIN INITIATIVES

Professional and Patient Education Resources Available from the Resource Center of the American Professional

Title	Summary of contents	Length	Price
Building an Institutional Commitment to Pain Management (Wisconsin Resource Manual, 2 nd edition)	This manual is based on recommendations for institutional change set forth in the Agency for Health Care Policy and Research (AHCPR- now AHRQ) clinical practice guidelines for acute and cancer pain, and the American Pain Society (APS) quality improvement guidelines. It provides a comprehensive plan and a list of resources to assist you to implement those guidelines. You will find suggestions for getting started, a process to follow, and tools you can use and/or adapt to your needs. It includes a CD ROM with the Sample Resource Tools and a Pain Management Quality Improvement Database. A great resource for implementing the new JCAHO pain standards!	375 pgs	\$25 (+\$5 s/h)
Effective Pain Management Practices in Home Health (7 video set)	The video set includes: 1. Pain Assessment- Simplifying the Complex; 2. Patient's Fears and Misconceptions About Pain and Opioids; 3. That Extra Pain Medication Didn't Help! What to Do When Your Patient is Getting Opioids, but is Still in Pain; 4. It Isn't Really Pain...Exactly: Treatment of Neuropathic Pain; 5. Managing Opioid Side Effects; 6. Pain Management Patient Education; 7. How to Talk to Doctors About Pain Management.	Each video is 10-15 minutes long	Seven video set: \$70 (+\$7 s/h) Individual videos: \$12 (+\$4 s/h)

<p>The Post-Operative Pain Management (POP) Quality Improvement Project-In-A-Box</p>	<p>This resource includes the manual, 'Building an Institutional Commitment to Pain Management,' the accompanying CD ROM, a Coordinator's Manual, APS Quality Improvement Guidelines for the Treatment of Acute Pain and Cancer Pain, APS Principles of Analgesic Use in the Treatment of Acute Pain and Cancer Pain, AHCPR Acute Pain Management in Adults: Operative Procedures, Clinical Practice Guidelines Quick Reference Guide, AHCPR Acute Pain Management in Infants, Children, and Adolescents: Operative and Medical Procedures; AHCPR Pain Control After Surgery: Clinical Practice Guidelines Patient Guide, ASA Practice Guidelines for Acute Pain Management in the Preoperative Setting; chapters from the Comprehensive Accreditation for Hospitals: the Official Handbook (CAMH) by the JCAHO, and more.</p>		<p>\$250</p>
--	--	--	--------------

Patient Education

Title	Summary of contents	Length	Price
<p>Cancer Pain Can Be Relieved</p>	<p>A nine-page pamphlet for patients and families. It contains answers to twenty common cancer pain questions. <i>Note: Permission to reproduce/photocopy this resource is granted as long as authorship is maintained.</i></p>	<p>9 pages</p>	<p>First copy: free, Additional copies: \$0.50</p>
<p>Eight Facts Everyone Should Know</p>	<p>A single page pamphlet covering eight facts everyone should know about cancer pain. <i>Note: Permission to reproduce/photocopy this resource is granted as long as authorship is maintained.</i></p>	<p>1 page</p>	<p>\$0.15</p>

Contact info:

The Resource Center of the AACPI
1300 University Ave. #4720
Madison, WI 53706
Phone: (608) 262-0978
Fax: (608) 265-4014
Website: www.aacpi.wisc.edu



AMERICAN ACADEMY OF PAIN MANAGEMENT

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
Pain Practitioner	Quarterly Newsletter	12-16 p.	Free
Ten Tips for Prescribing	Opioids Prescribing Rules	4	Free
Opioid Agreement	Prescriber's Agreement	12	Free

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
Find a Practitioner	Directory of American Academy of Pain Management Members	Data base on web site	Free

Contact: B. Eliot Cole, M.D., Director of Education
 Name: American Academy of Pain Management
 Address: 13947 Mono Way, Suite A, Sonoma, CA 95370
 Phone: 209-533-9744
 Email: Kimit@ix.netcom.com
 Web Site: www.aapainmanage.org



AMERICAN ACADEMY OF PAIN MEDICINE

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
The Use of Opioids for the Treatment of Chronic Pain	Position Statement – addressing misconceptions on opioid use for treatment.	4 pgs	Shipping (and additional costs for large orders)
Consent for Chronic Opioid Therapy	Position Statement – consent form between a patient and physician when prescribing opioids	2 pgs	Shipping (and additional costs for large orders)
The Necessity for Early Evaluation and Treatment of the Chronic Pain Patient	Position Statement – explains the need for early treatment	1 pg	Shipping (and additional costs for large orders)
Long-term Controlled Substances Therapy for Chronic Pain – Sample Agreement	Position Statement – consent agreement between a patient and physician when prescribing	2 pgs	Shipping (and additional costs for large orders)
Definitions Related to the Use of Opioids for the Treatment of Pain	Position Statement – outlining the various terms surrounding opioid treatment	4 pgs	Shipping (and additional costs for large orders)
A Pledge	Position Statement – pledge from medical providers regarding the ethical treatment of pain	1 pg	Shipping (and additional costs for large orders)
A Brief Guide to Pain Medicine Brochure	Brochure includes information on pain, Pain Medicine, pain treatment, pain facts, and organizational information	4 pg pamphlet	Shipping (and additional costs for large orders)

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
A Patient's Guide to Pain Medicine Brochure	Brochure includes information on pain, Pain Medicine physicians, benefits of appropriate pain treatment, consequences of mismanaged or undermanaged pain, pain facts and organizational information	4 pg pamphlet	Shipping (and additional costs for large orders)

Contact: American Academy of Pain Medicine

Name: Kim Kutska

Address: 4700 W Lake Avenue; Glenview, IL 60025

Phone: 847/375-4876

Email: kkutska@amctec.com

Web Site: www.painmed.org

Any of the above materials can be copied and sent to various locations for the cost of shipping. If a large amount of copies are requested, AAPM will charge a nominal fee to cover costs of the project.



AMERICAN ACADEMY OF PHYSICAL MEDICINE AND REHABILITATION

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
What is a Physiatrist?			Sample copy free
Low Back Pain Rehabilitation			Sample copy free
Physical Medicine & Rehabilitation: Diversity in a Profession			Sample copy free
Your Patients and the Physical Medicine & Rehabilitation Consultation			Sample copy free
Concepts in Care Brochure for Referring Physicians			Sample copy free
Concepts in Care Brochures for MCOs			Sample copy free
The Physiatrist's Guide to Practice Medicine			\$275 for non-members

Contact: American Academy of Physical Medicine and Rehabilitation

Name: Steve Smith

Address: One IBM Plaza, Suite 2500, Chicago, IL 60611-3604

Phone: 312-464-9700

Email: ssmith@aapmr.org

Web Site: www.aapmr.org



AMERICAN BACK SOCIETY

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
ABS Newsletter	A quarterly publication for Back Care Professionals	20 to 30 pages	\$62.50 for non-members

Contact: American Back Society

Name: Candy Lau

Address: 2647 International Boulevard, #401, Oakland, CA 94601

Phone: 510-536-9929

Email: info@americanbacksoc.org

Web Page: www.americanbacksoc.org



AMERICAN CHRONIC PAIN ASSOCIATION

We can offer the following materials for professional education and use:

Title	Summary of Contents	Pages/length	Charge
<i>American Chronic Pain Association Help and Hope</i>	Pamphlet that provides overview of who we are, skills helpful in managing pain, what we have learned.	trifold	Up to 25 free
<i>Coping With Chronic Pain: Helpful Advice from the American Chronic Pain Association</i>	Provides an overview of the ACPA Ten Steps From Patient to Person	trifold	Up to 25 free
<i>Pathways Through Pain: Accepting the Pain Video</i>	The first video in a series, <i>Pathways Through Pain: Accepting the Pain</i> focuses on the first-person accounts of ACPA members who have learned to manage their pain and regain control and quality in their lives through American Chronic Pain Association programs. The video will help to empower people, reduce isolation, and, by introducing basic principles of pain management, may help them to improve their level of functioning. The video provides a wonderfully positive look into the lives of people who are <u>living</u> with pain	20 minutes	\$40 non-members \$25 members
<i>Pathways Through Pain: Getting Involved Video</i>	The second of the series, <i>Pathways Through Pain</i> , this video draws on the personal experiences of people with pain to explore how becoming involved in your own care, learning about your health condition, and reengaging with family and friends can help individuals continue to move from patient to person and reduce their sense of suffering.	15 minutes	\$40 non-members \$25 members

Ten Steps From Patient to Person Video	The video, featuring Penney Cowan, founder of the ACPA, discusses the value of a multidisciplinary pain management program and what is necessary to maintain "wellness" long term. She also presents the ten steps necessary to move from patient to person	22 minutes	\$25 non-members \$22.50 members
<i>ACPA Family Manual</i>	Chronic pain is a family affair. Members of the family must deal with their own "pain" and stress resulting from the circumstances. The ACPA Family Manual can help family members manage lifestyle changes and difficulties due to living with a person in chronic pain and begin to rebuild a mutually supportive family unit.	149 pages	\$18.50 non-members \$16.65 members
<i>The ACPA Chronicle</i>	The <i>ACPA Chronicle</i> is a quarterly newsletter produced by the members of the American Chronic Pain Association. Each issue features a listing of new ACPA chapters established in that quarter, useful coping skills in pain management, inspiring and insightful articles by the members of the ACPA, book reports, and important information about the ACPA. The ACPA	16 pages	Sample free \$15 annually
<i>ACPA Medication Supplement 2003</i>		38pp	Free download on www.theacpa.org

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge?
<i>American Chronic Pain Association: Help and Hope</i>	Pamphlet that provides overview of who we are, skills helpful in managing pain, what we have learned.	trifold	Up to 25 free
<i>Coping With Chronic Pain: Helpful Advice from the American Chronic Pain Association</i>	Provides an overview of the ACPA Ten Steps From Patient to Person	trifold	Up to 25 free

<i>The American Chronic Pain Association Quality of Life Scale</i>	A 1 to 10 scale to help people with pain measure their level of functioning and track progress over time.	1 page	Up to 25 free
<i>ACPA Medication Supplement 2003</i>		38pp	Free download on www.theacpa.org
<i>From Patient to Person: First Steps</i>	Begin your journey from patient to person with this 190-page workbook designed to help anyone who has a chronic pain problem gain an understanding of how to cope with the problems that their pain creates.	199 pp.	\$25 non members \$20 members
<i>The ACPA Chronicle</i>	The <i>ACPA Chronicle</i> is a quarterly newsletter produced by the members of the American Chronic Pain Association. Each issue features a listing of new ACPA chapters established in that quarter, useful coping skills in pain management, inspiring and insightful articles by the members of the ACPA, book reports, and important information about the ACPA. The ACPA	16 pp.	Sample free \$15 annually
<i>Staying Well: Advanced Pain Management for ACPA Members</i>	This workbook is designed for those who have a working knowledge of the basics of pain management. This workbook provides additional skills necessary to continue to move forward in the journey to wellness	153 pp.	\$17.50 non members \$15.75 members
<i>ACPA Facilitator Guide and materials</i>	This guide will aid you and others in your community organize an ACPA chapter. The manual contains how-to information on organizing an ACPA chapter, sharing responsibility for the group with others, finding a meeting place, conducting the first meeting, and generating public interest in your area. You must be an ACPA member to purchase this manual.	99pp	\$7, must be a member of ACPA

<i>ACPA Family Manual</i>	Chronic pain is a family affair. Members of the family must deal with their own "pain" and stress resulting from the circumstances. The ACPA Family Manual can help family members manage lifestyle changes and difficulties due to living with a person in chronic pain and begin to rebuild a mutually supportive family unit	149 pp	\$18.50 nonmember \$16.65 member
<i>Reflections of You: Personal Journal and Medication Book</i>	<i>Reflections of You</i> is a daily meditation and personal journal which offers positive and motivating thoughts to stimulate your thinking and challenge you to personal growth. Your daily entries in the journal will help you track your progress and show when you have reached your personal goals. The book is spiral bound for ease in making daily entries into the journal.	366pp	\$25 nonmember \$22.50 member
<i>ACPA Kits for Wellness</i>	With the growing need of many ACPA members to have additional materials that will help them progress in their understanding of pain management, a new series of educational materials is available. Each kit focuses on one area of pain management and allows members to work either with an ACPA group or independently. The new kits are filled with worksheets designed to create awareness and understanding of the role the person with pain must assume. The kits are: Kit One - Understanding Chronic Pain: At the Time of Diagnosis \$3.30 Kit Two - Accepting the Pain \$2.90 Kit Three - Getting Involved \$4.20 Kit Four - Priorities \$3.40 Kit Five - Setting and Evaluating Personal Goals \$4.20 Kit Six - Your Basic Rights \$7.30		

<i>ACPA Coping Calendar 2003</i>	A useful tool in your continued quest as you make the transition from patient to person, the calendar highlights a basic coping skill each month. Throughout the month there are daily reminders related to that month's skill. Perfect for gift giving!		\$10
<i>Pain Relief and Breath Relaxation</i> tape or CD	Part 1, Pain Relief , is designed to create a state of deep relaxation. It is also capable of producing a significant reduction in the amount of discomfort one feels. Part 2, Breath Relaxation is designed to teach ways to focus awareness on your breathing. Learning to control your breathing can often help reduce anxiety and enhance relaxation.		CD \$12.50 Tapes \$10
<i>Autogenic Relaxation and General Relaxation</i> tape or CD	Side one, Autogenic Relaxation or " <i>self control training</i> " uses repetition of key phrases and images to facilitate feelings of relaxation and calm. Side two, "General Relaxation" , is designed for deep relaxation. To promote a growing sense of peace in both your mind and body		CD \$12.50 Tapes \$10

Contact: American Chronic Pain Association
Address: Post Office Box 850, Rocklin, CA 95677
Phone: 916-632-0922
Email: www.acpa@pacbell.net
Web Site: www.theacpa.org



AMERICAN PAIN FOUNDATION

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
Power Over Pain	Community Action Kit & Media Guide	100	Shipping charge of \$15

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
Finding Help for Your Pain	Guide to getting treatment	16 page booklet	S & H
Pain Action Guide	Pain Information	12page booklet	S & H
Bill of Rights	Rights of Pain Patient	1 card	S & H
Bill of Rights in Spanish	Rights of Pain Patient	1 card	S & H

ACTION IDEA: Pain Screening Workshop for Healthcare Providers and Other Caregivers

Target Group: Healthcare providers and caregivers

Why:

Until recently, pain was greatly overlooked by healthcare providers as a healthcare problem, and pain screening has not been part of routine examinations. Also, those caring for people who are ill, have not been trained to ask specific questions about pain. The result is that many people with pain are not getting the care they need.

What:

These workshops will be presented by healthcare professionals, who are trained in pain management, for the purpose of providing other healthcare providers and caregivers with "pain screening basics."

The workshop format will include a prepared power point or slide presentation (included in this section) followed by a Q & A.

Goals:

Raise consciousness among healthcare providers about the importance of pain screening

Teach healthcare providers how to screen for pain

Teach caregivers to screen for pain, and reinforce the concept that this can be done by lay persons as well as professionals

Who Should Attend:

Physicians and physician assistants

Nursing and medical assistants

Therapists: physical, behavioral, occupational, and recreational

Caregivers, including friends, family, and clergy

Where:

Live presentations can be held in any location that is easy-to-get-to and conducive to learning. Think creatively. Offer this workshop to local churches, senior and community centers, Y's, hospitals, etc. This can also be a self-learning workshop, where participants use prepared packets or work on-line.

When:

Because these are fairly simple to organize these can be done at a variety of times.

Materials:

The power point presentation is available on the *Power Over Pain* section of the American Pain Foundation website. A slide set can be borrowed from the American Pain Foundation.

Hand-outs may include: numeric /faces pain scales, AHCPA Acute Pain and/or Cancer Pain Guidelines, Pain Care Bill of Rights, and a sample pain journal.

Contact: Education Department

Name: American Pain Foundation

Address: 201 North Charles Street, Suite 710, Baltimore, MD 21201-4111

Phone: 888-615-7246

Email: info@painfoundation.org

Web Site: www.painfoundation.org



AMERICAN PAIN SOCIETY

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
The Use of Opioids for the Treatment of Chronic Pain	Position and Consensus Statements	2-4 pages 8 ½ by 11	(<25 – no charge) 25+ 20cents each
Promoting Pain Relief and Preventing Abuse of Pain Medication: A Critical Balancing Act	Position and Consensus Statements	2-4 pages	(<25 – no charge) 25+ 20cents each
The Assessment and Management of Acute Pain in Infants, Children, and Adolescents	Position and Consensus Statements	2-4 pages	(<25 – no charge) 25+ 20cents each
Definitions Related to the Use of Opioids for the Treatment of Pain	Position and Consensus Statements	2-4 pages	(<25 – no charge) 25+ 20cents each
Pediatric Chronic Pain; A Position Statement from the American Pain Society	Position and Consensus Statements	2-4 pages	(<25 – no charge) 25+ 20cents each
Pain Care Coalition	Position and Consensus Statements	2-4 pages	(<25 – no charge) 25+ 20cents each
Weekly Washington Wire On Health Care Issues	Position and Consensus Statements	2-4 pages	(<25 – no charge) 25+ 20cents each
Healthcare Policy Statement	Position and Consensus Statements	2-4 pages	(<25 – no charge) 25+ 20cents each
Pain Assessment and Treatment in the Managed Care Environment	Position and Consensus Statements	2-4 pages	(<25 – no charge) 25+ 20cents each
How to Use the APS Position Statement: Pain Assessment and Treatment in the Managed Care Environment	Position and Consensus Statements	2-4 pages	(<25 – no charge) 25+ 20cents each
Quality Improvement Guidelines for the Treatment of Acute Pain and Cancer Pain	Position and Consensus Statements	2-4 pages	(<25 – no charge) 25+ 20cents each
Treatment of Pain at the End of Life	Position and Consensus Statements	2-4 pages	(<25 – no charge) 25+ 20cents each

Contact: Member Services

Name: APS

Address: 4700 W Lake Ave., Glenview, Illinois 60025-1485

Phone: 847-375-4715

Email: info@ampainsoc.org

Website: www.ampainsoc.org



AMERICAN RSDHOPE GROUP

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
Packet – RSDS	Basic information on Reflex Sympathetic Dystrophy Syndrome	40	Free

Contact: American RSDHope Group
 Address: Post Office Box 875, Harrison, ME 04040-0875
 Phone: 207-799-8056
 Web Page: www.RSDHope.org



AMERICAN REHABILITATION NURSES

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
ARN Professional Resources Catalog			Free
ARN Conference Brochure			Free
ARN Role Descriptions			Free
CRRN Certification Handbook			Free

Contact: American Rehabilitation Nurses

Name: Angie Forbes

Address: 4700 West Lake Avenue, Glenview, IL 60025-1485

Phone: 847-375-4760

Email: afortbes@amctec.com

Web Site: www.rehabnurse.org



AMERICAN SOCIETY OF PERIANESTHESIA NURSES

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
Pain Management Imperatives #81	Presented by: Vallire Hooper, MSN, RN, CAPA & Kathleen Miller, MSN, RN, CPAN	1 VHS Video	\$154.00
Anatomy, Physiology, and Pharmacology #82	Presented by: Vallire Hooper, MSN, RN, CAPA & Kathleen Miller, MSN, RN, CPAN	1 VHS Video	\$154.00
Pain Assessment in the PeriAnesthesia Setting #83	Presented by: Vallire Hooper, MSN, RN, CAPA & Kathleen Miller, MSN, RN, CPAN	1 VHS Video	\$154.00
Acute Pain #84	Presented by: Vallire Hooper, MSN, RN, CAPA & Kathleen Miller, MSN, RN, CPAN	1 VHS Video	\$154.00
Chronic Pain #85	Presented by: Vallire Hooper, MSN, RN, CAPA & Kathleen Miller, MSN, RN, CPAN	1 VHS Video	\$154.00
Complete Series Numbers 81 – 85	Presented by: Vallire Hooper, MSN, RN, CAPA & Kathleen Miller, MSN, RN, CPAN 9.3 Contact Hours Available	5 VHS Videos	\$375.00
ASPAN Pain and Comfort Resource Manual	Comprehensive guideline for assessing and treating patient pain and comfort. Contents below.	Available in the Fall 2003	

Contact: American Society of PeriAnesthesia Nurses (ASPAN)

Name: Diane Bradley

Address: 10 Melrose Ave.* Suite 110 * Cherry Hill, New Jersey 08003

Phone: 856-616-9600 x16

Email: aspan@aspan.com

Web Site: www.aspan.org

**ASPAN PAIN AND COMFORT
RESOURCE MANUAL**
Table of Contents 2003 Edition

Presidential Commentary.....	7 – 9
Introduction.....	10
Dina A. Krenzischek, MAS, RN, CPAN	
Executive Summary.....	11
Dina A. Krenzischek, MAS, RN, CPAN	
ASPANs’ Statements.....	12
Patient’s Rights (Derived from JCAHO).....	13
Dina A. Krenzischek, MAS, RN, CPAN	
Indication for Pain and Comfort Guidelines / Responsibilities.....	14 - 15
Dina A. Krenzischek, MAS, RN, CPAN	
ASPAN Pain and Comfort Guidelines.....	16 - 23
Dina A. Krenzischek, MASRN,CPAN	
Competency Based Credentialing Program:	
Pain / Comfort Management.....	24 - 46
Kathleen Miller, MSN, RN, CPAN	
Marie Barmore Wiegart, BSN, RN, CPAN, CAPA	
Lois Schick, MN, MBA, RN, CPAN, CAPA	
Advance Pain Management.....	
Linda Ziolkowski, MSN, RN, CPAN, APRN, BC	
Advance Comfort Management.....	47 - 62
Kathy Kolcaba, PhD, RN,C	
Table of Contents (cont.)	
<u>Categories</u>	<u>Pages</u>
Advance Pediatric Pain Management.....	63 - 76
Dolly Ireland, MSN, RN, CAPA	
Advance Geriatric Pain Management.....	77 - 82
Jane Coyle, RN	
Needs Assessment: Pain and Comfort Management.....	83 - 85
Dina A. Krenzischek, MAS, RN, CPAN	

Practical Guide:	
Legal	86
Ellen Sullivan, BSN, RN, CPAN	
Documentation	86
Ellen Sullivan, BSN, RN, CPAN	
Integrative Therapies:	
Relaxation Techniques.....	87 - 88
Cutaneous Stimulation.....	88
Distraction.....	89
Music Therapy.....	90
Imagery.....	90
Herbal Therapies.....	90 - 91
Ellen Sullivan, BSN, RN, CPAN	
Theresa Clifford, MSN, RN, CPAN	
Culturally Diverse Patients:	
Indian.....	91
African American.....	92
Puerto Rico.....	92
Japanese.....	92 - 93
Chinese.....	93
Russian.....	93
Arab	93 - 94
South Asians.....	94
Meg Bertune, BSN, RN, CPAN	
Ellen Sullivan, BSN, RN, CPAN	
Patients with Special Needs.....	94 - 100
Dina A. Krenzischek, MAS, RN, CPAN	
Table of Contents (cont.)	
<u>Categories</u>	<u>Pages</u>
Educational Resources:	
Patient and Family Teaching Guide (English version).....	101 - 103
Laura Habighorst, RN, CAPA	
Susan Shelander, RN, CPAN	
Patient and Family Teaching Guide (Spanish version).....	104 - 106
Bill Gough, CRNP (Translator)	
Relaxation Exercises	107 - 108

American Pain Society	
Pain Care Bill of Rights (English and Spanish versions)..... American Pain Society	109
Patient Talking About Pain (English and Spanish versions)..... American Pain Society	110
PCA Patient Teaching..... Dina A. Krenzischek, MAS, RN, CPAN	111
Clinician's Quick Guide..... Myrna Mamaril, MS, RN, CPAN, CAPA Bonnie Rosenthal, BSN,RN,CPAN Sandie Bryan, RN, CPAN	112
Questions and Answers..... Dina A. Krenzischek, MAS, RN, CPAN	113 - 115
Methods for Pain and Comfort Assessment..... References	116 - 117
Initial Pain Assessment Tool..... Reference	118
Pain and Comfort Nursing Documentation Dictionary..... Dina A. Krenzischek, MAS, RN, CPAN	119 - 120
Table of Contents (cont.)	
Pain Management Anesthesia Dictionary..... American Society of Perianesthesia	121
Performance Improvement (PI)	
JCAHO PI Practical Guide.....	122 - 123
Patient Satisfaction Survey..... Dina A. Krenzischek, MAS, RN, CPAN	124 - 125
<u>Categories</u>	<u>Pages</u>
Documentation Audit..... Reference	126

Patient Survey Questions.....	127
Reference	
Performance Improvement Step by Step Approach.....	128 - 130
Dina A. Krenzischek, MAS, RN, CPAN	
13. Research	
Practical Points in Developing Research.....	132 – 133
Pamela Windle, MS,RN,CAN,CPAN	
Dissemination of Findings.....	134
Dina A. Krenzischek, MAS, RN,CPAN	
14. Others:	
a. Press Release Statement.....	135 - 136
Mauren Iacono, BSN, RN, CPAN	
Selected References.....	136 - 139
Nancy Saufl, MS, RN, CPAN, CAPA	
c. Other Resources.....	137 – 140
d. Attachments.....	141



CHRONIC FATIGUE

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
Chronic Fatigue Syndrome: A Diagnostic and Management Challenge	The provider education project is a collaborative effort of the CFIDS Association of American and the Centers for Disease Control and Prevention (CDC) and is designed to teach health care providers how to better recognize and manage CFS and includes; case definition, history, theories of etiology, myths surrounding CFS, diagnosis, management, disability and prognosis.	Modules available in print – (2 hours of study), video- (three hours of study) or Web based (two hours of study) formats	All formats are free of charge for health care providers

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
Offprints	We offer a variety of research articles on general CFS issues as well as specific topics, such as neuroendocrine dysfunction or dysautonomias.		

Contact: The CFIDS Association of America
 Name: Terri Lupton, RN, Coordinator of Educational Opportunities
 Address: Post Office Box 220398, Charlotte, NC 28222
 Phone: 704-364-0488
 Email: meded@cfids.org
 Web Site: www.cfids.org



CITY OF HOPE PAIN/PALLIATIVE CARE RESOURCE CENTER (COHPPRC)

April, 2003 edition
(updated monthly)

Index/Order Form of Materials

The purpose of the COHPPRC is to serve as a clearinghouse to disseminate information and resources to assist others in improving the quality of pain management and palliative care. The COHPPRC, established in 1995, is a central source for collecting a variety of materials including pain assessment tools, patient education materials, quality assurance materials, palliative care resources, research instruments and other resources.

If you have materials that may be useful to others related to pain management or palliative care, you are invited to contribute them. Please contact Stacey Pejsa or Betty Ferrell, RN, PhD, FAAN at the City of Hope for a materials submission form so that you will be properly credited for your contribution. Attached is the Index of Materials that is available for ordering through the COHPPRC.

There is a nominal fee for ordering written materials from the Index to help defer the cost of printing and mailing.

Please note that the W indicates items that are available at no cost on our Website

(<http://prc.coh.org>). The last page of the index contains the mailing and background information of the individual requesting materials to be mailed. So that we may better serve you, please be sure to complete this information in its entirety. **Note: We are able to accept U.S. currency only.** Please feel free to copy this index of materials and distribute to whomever you feel would benefit from this service.

City of Hope Pain/Palliative Care Resource Center
1500 East Duarte Road
Duarte, CA 91010
Phone: (626) 359-8111 ext. 63829
FAX: (626) 301-8941
Website: <http://prc.coh.org>



TABLE OF CONTENTS

I.	<i>Quality of Life</i>	53	
II.	<i>Nursing Knowledge, Education Programs, and Professional Competency</i>	54	
III.	<i>Patient Education</i>	59	
IV.	<i>Pain in the Elderly</i>	65	
V.	<i>Quality Improvement</i>	68	
VI.	<i>Ethics</i>	71	
VII.	<i>Family/Home Care</i>	73	
VIII.	<i>Pharmacology/Policies and Procedures</i>	75	
IX.	<i>Pediatrics</i>	82	
X.	<i>Costs</i>	86	
XI.	<i>End of Life/Palliative Care</i>	87	
XII.	<i>Palliative Surgery</i>	96	
XIII.	<i>Culture</i>	97	
XIV.	<i>Sickle Cell</i>	98	
XV.	<i>HIV/AIDS</i>	100	
XVI.	<i>Research Instruments</i>	101	
XVII.	<i>Legal/Regulatory Issues</i>	106	
XVIII.	<i>Pain Assessment Tools</i>	106	
XIX.	<i>Related Organizations and Websites</i>	108	
XX.	<i>Other Resources</i>	113	
XXI.	<i>Emergency Room Information</i>	119	
XXII.	<i>Headache Information</i>	119	
XXIII.	<i>Non Drug Pain Interventions</i>	120	

CITY OF HOPE PAIN/PALLIATIVE CARE RESOURCE CENTER
Index of Materials

Unless otherwise noted, all materials are \$3.00 each copy to cover our expenses for copyright charges, printing and mailing. Under each section, materials are organized under the following categories:

- | | |
|----|----------------------------------|
| A. | City of Hope Publications |
| B. | Recommended Books |
| C. | Educational Materials/Curriculum |
| D. | Guidelines/Clinical Pathways |
| E. | Other Organizations Links |
| F. | Key References |
| G. | Position Statements/Standards |

Quality of Life

Section Description: This section includes City of Hope Publications and figures of the City of Hope Quality of Life conceptual model.

For more information on measurement tools for Pain and Quality of Life, refer to Section 0. Research Instruments in this Index.

A. City of Hope Publications

_____ Vallerand A, Ferrell BR. (1995). "Issues of control in patients with cancer pain." Western Journal of Nursing Research, 17(5): 467-483 - The concept of control is analyzed from the perspective of the patient, family caregiver and nurse. Suggestions are made for interventions to increase control for patients in pain.

_____ Ferrell BR. (1995). "The impact of pain on quality of life: A decade of research." Nursing Clinics of North America, 30(4): 609-624 - Summarizes Ferrell's program of research from 1984-1994 and evolution of the conceptual model of pain and quality of life.

_____ Ferrell BR, Funk B. (1995). "Management of breast cancer pain." Innovations in Breast Cancer Care, 1(1): 9-13. - A review of pain as it relates to breast cancer and its effect on quality of life are emphasized.

_____ Ferrell BR (1996). "The Quality of Lives: 1,525 Voices of Cancer." Oncology Nursing Forum, 23(6): 907-916.

_____ Quality of Life Models – all of the models include a list of references

W

Quality of Life Breast Cancer
Quality of Life Cancer Survivor
Quality of Life Fatigue

Quality of Life Pain
Quality of Life Bone Marrow Transplant
Quality of Life Family Caregiver
Quality of Life Ovarian Cancer

B. Recommended Books

Quality of Life: From Nursing and Patient Perspectives by Cynthia R. King and Pamela S. Hinds.

Published by Jones and Bartlett Publishers, Sudbury, Massachusetts, 1998. To order online visit Jones and Bartlett Publishers website at <http://www.jbpub.com/> (search for "Quality of Life" on the website)

Quality of Life & Pharmacoeconomics: An Introduction

This book will familiarize students, clinicians, and researchers with the key principles and methods of quality-of-life and cost-effectiveness assessment in clinical trials. The book is based on abstracted material from the Second Edition of Dr. Spilker's definitive reference, *Quality of Life and Pharmacoeconomics in Clinical Trials* (1996). Website:

<http://www.lww.com/products/?525300912>

C. Educational Materials/Curriculum

D. Guidelines/Clinical Pathways

E. Other Organizational Links

International Society for Quality of Life Research

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

F. Key References

G. Position Statements/Standards

Nursing Knowledge, Education Programs, and Professional Competency

Section Description: This section includes materials from previous Pain Resource Nurse (PRN) programs at the City of Hope and similar programs including agendas, objectives, tests, and syllabi. Additional resources include self-paced learning modules, pain management competency packets and curriculum, treatment and training guidelines, and case conference packets. These resources are available in various forms such as interactive CD-ROM, video tapes, and bound copies.

For measurement tools on *Nurses' Knowledge and Attitudes* refer to Section 0. Research Instruments on this Index of Materials.

A. City of Hope Publications

McCaffery M, Ferrell BR. (1994). "Understanding opioids & addiction." *Nursing94*, 24(8): 56-59 - This article includes a 5-item quiz to test knowledge about opioid addiction. Six strategies are discussed to dispel myths and barriers associated with taking opioids for pain relief. The terms psychological dependence (addiction), physical dependence, and tolerance are clearly defined.

Ferrell BR, McCaffery M, Rhiner M. (1992). "Pain and addiction: An urgent need for changing nursing education." *Journal of Pain and Symptom Management*, 7(2): 117-124 - This article emphasizes the lack of education about pain management as a result of

inaccurate or confusing statements about addiction, dependence, and tolerance made in nursing textbooks.

_____ Ferrell BR, Grant M, Ritchey KJ, Ropchan R, Rivera LM. (1993). "The Pain Resource Nursing Training program: A unique approach to pain management." Journal of Pain and Symptom Management, 8(8): 549-556 - This article describes an innovative pain management program developed by the City of Hope Medical Center which included 26 RNs' in a 40-hour didactic course. The purpose of this course was to designate a pain resource nurse (PRN) as a staff nurse advocate for improved pain relief. The curriculum for the training program is outlined.

_____ Ferrell BR, McCaffery M. (1997). "Nurses' knowledge about equianalgesia and opioid dosing." Cancer Nursing, 20(3): 201-212 - This article reports results from a study which evaluated nurse's knowledge regarding three methods of analgesic delivery that have become common in clinical practice.

_____ McCaffery M, Ferrell BR. (1997). "Nurses' knowledge of pain assessment and management: How much progress have we made?" Journal of Pain and Symptom Management, 14(3): 175-188 - This article explores indications of progress in the level of nursing knowledge about basic aspects of pain management. The literature is reviewed and findings from surveys of nurses' knowledge from 1988-1995 are compared.

_____ Ferrell BR, Virani R. (1998). "Institutional commitment to improved pain management: Sustaining the effort." Journal of Pharmaceutical Care in Pain & Symptom Control, 6(2): 43-55 - Survey of institutions who have implemented a Pain Resource Nurse program.

_____ McCaffery M, Ferrell BR. (1997). "Influence of professional vs. personal role on pain assessment and use of opioids." The Journal of Continuing Education in Nursing, 28(2): 69-77 - Study evaluating impact of personal experience/knowledge on nurses decisions in pain management.

_____ McCaffery M, Ferrell BR. (1999). "Opioids and pain management - What do nurses know?" Nursing, 29(3): 48-52 - Surveys focus on two familiar nursing activities: assessing pain intensity and administering opioid analgesics.

_____ McCaffery M, Ferrell BR, Pasero C. (2000). "Nurses' Personal Opinions about Patients' Pain and Their Effect on Recorded Assessments and Titration of Opioid Doses." Pain Management Nursing, 1(3): 79-87 - Surveys nurses' decisions about assessment and treatment of pain in 2 patient situations and confirms that nurses continue to undertreat severe pain. Results reveal nurses' personal opinions about the patients' pain, rather than their recorded assessments, influence choice of opioid dose and to contribute to undertreatment of pain.

B. Recommended Books

_____ **W** Pain: Clinical Manual 2nd Edition by McCaffery & Pasero, 1999 book order form - this manual is an invaluable guide to an interdisciplinary approach in the care of patients with pain. ISBN #: 0-8151-5609-X (29563). Visit <http://www.mosby.com> to order. (enter ISBN # or search for pain on website to find this item)

C. Education Materials/Curriculum

-
- W** Pain Resource Nurse Training Program Packet - City of Hope, Duarte, California
- Agenda and objectives developed for a 5-day Pain Resource Nurse Training Program – 1996 version
 - Agenda and objectives developed for a 3-day Pain Resource Nurse Training Program – 2001 version

-
- W** Pain Resource Nurse Training Program Packet - U. of Wisconsin Hospital & Clinics, Madison, WI.
- Pain Resource Professional Program - this is a description of a 3-day course outline with time frames, topics, speakers and objectives (2002 version).
 - Privilege: Pain Resource Nurse - guidelines developed for job evaluation and performance criteria to be utilized for annual review of the Pain Resource Nurse position
 - Pain Resource Nurse Role: Description and Responsibilities - Purpose and Policy governing description and responsibilities of the Pain Resource Nurse role
 - Post-test - Pain Resource Nurse Training Program - this 47 question post-test is developed for the Pain Resource Nurse Training Program (2002 version)

-
- W** Self Learning Pain Module - Kaiser Permanente - Los Angeles, California
Developed by CQI Team for cancer pain. A self-learning module based on current standards of care in pain management (1995 version)

-
- W** Pain Management Competency Packet – To assist preceptors to provide feedback to new nurses on ability to assess and manage pain. These tools define the competencies for clinical nurses in hospitals with a structured pain program.
- City of Hope National Medical Center (1997 version)
- Developed by the Department of Nursing Research and Education
- U. of Wisconsin Hospital & Clinics, Madison (1995 version)
- Developed by the Patient Care Team

-
- W** Guidelines for Pain Case Conferences packet - U. of Wisconsin Hospital & Clinics, Madison, WI
- Summary of identification, organization, and objectives in establishing a pain case conference for an individual patient (1996 version).
 - Summary of goals, objectives, and format in establishing pain case conferences to improve pain management (1996 version).

-
- W** Packet of Resources on Pain Management - Margo McCaffery, RN, MS, FAAN
- *Video*: Contemporary Issues in Pain Management video series order form - Williams & Wilkins Electronic Media. This video series addresses the problems nurses encounter in daily practice. Videos include Pain in Infants and Children, Pain in the Elderly and the Physiology and Pharmacologic Management of Pain. ISBN #: 0-683-17164-X. Visit website to order: <http://www.jww.com> (enter ISBN # or search for pain on website to find this item)
 - *CD-ROM*: Pain Management CD-ROM (Order form) – M. McCaffery and C. Pasero. Contents include: CD 1- Assessment & Overview of Analgesics (ISBN #: 0-7817-3986-1); CD 2-The Nurse’s Active Role in Opioid Administration (ISBN #: 0-7817-

3989-6). Visit website to order: <http://www.lww.com> (enter ISBN # or search for pain on website to find this item)

W

Competency Guidelines for Cancer Pain in Nursing Education and Practice - Wisconsin Cancer Pain Initiative

- Criteria used as basic competency in pain management for nurses. Useful for student evaluation or to establish clinical competency of nurses (1996 version).

Pain Management Curriculum for Skilled Nursing (RN and LVN Materials) - VNA and Hospice of Northern California (\$5.00/ copy)

- Curriculum objectives developed to improve staff knowledge, attitudes and practices regarding pain control, contributing to the ultimate goal of reducing or eliminating needless suffering among nursing home residents (1995-1996 version).

Pain Management Curriculum for Skilled Nursing (CNA, MSW, Rehab Materials) - VNA and Hospice of Northern California (\$5.00/ copy)

- Curriculum objectives developed improving staff knowledge, attitudes and practices regarding pain control, contributing to the ultimate goal of reducing or eliminating needless suffering among nursing home residents (1995-1996 version).

W

Nurses Self Paced Learning Module on Pain Management - Dominican Santa Cruz Hospital, Santa Cruz, CA

- Learning module directed at nurses in the area of pain management (1998).

Training Programs

W

- Palliative Care/Pain Management - listing of preceptorships, fellowships and pain training programs for nurses, physicians and others (1999 version)

- University of Pittsburgh Cancer Institute – “Facilitating the Management of Cancer Pain” - on-line educational offering.

The Program in Palliative Care Education and Practice

W

A “train the trainers” palliative care course offered twice a year at Harvard University for medical and nursing educators. Registration information provided through Website: <http://www.hms.harvard.edu/cdi/pallcare>

Pain Education That Feels Good Pain Management CD-ROM – Susan Pendergrass, MSN, RNCS, RNP & Judith Paice, PhD, RN, FAAN

W

An interactive multimedia Pain Management course offered on CD-ROM and the Internet intended for nurses and other healthcare providers working to relieve pain. This training, approved for 7 contact hours, addresses the problem of pain under-treatment through computer based education. Lectures, exercises, animation, interaction and extensive references help you master the philosophy, neurophysiology, assessment and management of pain including issues of pharmacological and non-pharmacological interventions and special populations. The training also incorporates the latest WHO and AHRQ guidelines. ISBN: 1-929466-02-1. Order through website at <http://www.graphiced.com>

Pain Assessment: “The Fifth Vital Sign” –State of California Board of Registered Nursing (effective 2/00)

W

Policy statement from the California Board of Registered Nursing that describes requirement of all health care staff to record pain assessment with vital signs. View online

at <http://www.rn.ca.gov/policies/policies.htm>

W

Effective Pain Management Practices in Home Health (video flyer) - The Resource Center of the American Alliance of Cancer Pain Initiatives

A series of seven videos designed to teach pain management skills.

Health Facts for You - Booklets developed by U. of Wisconsin Hospital & Clinics, Madison, WI (1997 version)

- Developing and Using Patient Teaching Guidelines

Developing *Health Facts for You*: An Author's Guide

W

Pain Management: An Interactive CD-ROM for Clinical Staff Development (Info Sheet Only)

T. Sierzant, J. Bauman Portu, M. Belgrade, M. Cook, M. Shepherd et al.

Abbott Northwestern Hospital, Minneapolis, Minnesota (2000 version)

A comprehensive pain management training tool based on evidenced-based procedures and AHRQ guidelines. It is completely interactive with video clips demonstrating patient interactions. 6-7.2 hours of CEU credits are available for nurses, physicians and pharmacists, and an economical approach to comprehensive staff training is offered.

ISBN # 0834219034. Order online through Website: <http://www.aspenpublishers.com>

Nursing Care of the Patient in Pain

W Online class conducted by Dr. Jo Eland that provides advanced content in the area of pain management for undergraduate and graduate nursing students. Content will focus on assessment, pharmacological and non-pharmacological nursing intervention, and evaluation of acute, chronic benign, and chronic malignant pain. Requirements include 2 online exams and a limited project that may be submitted electronically. For more information visit the University of Iowa Center for Credit Programs website at <http://www.uiowa.edu/~ccp/> (on website, search for online courses)

Disseminating End-of-Life Education to Cancer Centers (DELEtCC)

W A national educational program to prepare interdisciplinary healthcare providers as clinical leaders in end-of-life care for cancer patients and their families. The program is supported by a grant from The National Cancer Institute and sponsored by City of Hope National Medical Center. Website: <http://deletcc.coh.org>

D. Guidelines/Clinical Pathways

W Standards of Clinical Practice for the Specialty of Pain Management Nursing
Published by the American Society of Pain Management Nurses (ASPMN). Order form available to members of ASPMN on website: <http://www.aspmn.org/>

E. Other Organizational Links

American Society of Pain Management Nurses <http://www.aspmn.org/>
Hospice and Palliative Nurses Association <http://www.hpna.org/>

F. Key References

G. Position Statements/Standards

W Academy of Medical Surgical Nurses (AMSN) official position statement on pain management. Website: <http://www.medsurgnurse.org>

American Society of Pain Management Nurses Standards of Clinical Nursing Practice and Standards of Care – 2002 version

W Standards of Clinical Practice for the Specialty of Pain Management Nursing
Standards of Clinical Nursing Practice for Pain Management
Website: <http://www.aspmn.org>.

Patient Education

Section Description: This section includes educational kits and books, instructional guides and videos and health information sheets on various procedures.

A. City of Hope Publications

Ferrell BR, Rhiner M, Ferrell BA. (1993). "Development and implementation of a pain education program." *Cancer*, 72: 3426-3432 - A pain education program was developed, implemented, and evaluated in cancer patients and family caregivers. The investigators present the development and structure of the three-part education program, general principles of education regarding pain and methods of evaluating pain education.

Ferrell BR, Rhiner M. (1994). "Managing cancer pain. A three-step approach."

Nursing94, 24(7): 56-59- Describes a 3-step pain education program for cancer patients including 1) pain assessment; 2) drug treatment; and 3) non-drug methods to enhance pain relief such as heat, cold, massage/vibration and relaxation.

Ferrell BR, Ferrell BA, Ahn C, Tran K. (1994). "Pain management for elderly patients with cancer at home." Cancer, 74: 2139-2146 – Describes outcomes of 66 elderly patients with cancer who participated in a pain education intervention study. Results showed an increase in self-administration of pain medication and non-drug interventions a result of pain education.

Ferrell BR, Rivera LM. (1997). "Cancer pain education for patients." Seminars in Oncology Nursing, 13(1): 42-48 - Reviews basic principles of pain education and presents model examples of programs which have implemented innovative programs.

Ferrell BR, Juarez G (2002). "Cancer Pain Education for Patients and the Public." Journal of Pain and Symptom Management, 23(4): 329-336 – This article reports on the implementation of a national training project, Cancer Pain Education for Patients and the Public (CPEPP). The CPEPP curriculum was designed to address the multiple opportunities for pain education and to provide resources and support for successful implementation.

B. Recommended Books

"Living With Chronic Pain One Day At A Time" book order form.- St. Paul, Minnesota (1995)

W

Daily meditations developed by Mark Allen Zabawa. A patient's guide to living with chronic pain.

"Cancer Doesn't Have to Hurt" book order form - Hunter House Publishers, Alameda, California

W

- A 1997 book written by Pamela J. Haylock, RN and Carol P. Curtiss, RN for patient and public cancer pain education.

"Time to Say Goodbye: A Guide to Empowerment During Illness and Aging" book order form – Barbara Olive, RN/Limieux Publishing 1998

W

This book is written by a nurse as "your guide to empowerment during life threatening illness, aging, and life's final passages." It offers practical advice on how to tell a loved one about the terminal illness, put together a living will, develop comfort with pain medication, make choices about where to die, and grief stages. The chapters are supplemented with local and national resources. The book is available for \$14.95 from Eldercare Health, P.O. Box 170134, Milwaukee, WI 53217 or by calling (800) 950-7723. Website at <http://www.eldercaregivinghealth.com>, e-mail: barbrolive@aol.com

C. Educational Materials

City of Hope Patient Handbook for Cancer Pain Management English Version - City of Hope, Duarte, California (1994 version)

Developed by the Supportive Care Committee at City of Hope, this book was developed to help patients care for their pain, or for caregivers to help a loved one in pain. This booklet teaches how to assess your pain and actively participate in its management.

City of Hope Patient Handbook for Cancer Pain Management Spanish Version (Folleto sobre Como Tratar con el Dolor del Cancer para los Pacientes de City of Hope) - City of Hope, Duarte, California [Spanish version of Item #1 in this category (above)]

Packet of Health Facts

W Health Facts for You - Flyers developed by U. of Wisconsin Hospital & Clinics, Madison, WI

- Patient Controlled Analgesia (1999 version)
- Pain Management - What Everyone Should Know (2000 version)
- Nondrug Strategies (2000 version)
- Constipation from Opioids (Narcotics) (2000 version)
- Coping with Chronic Pain (2001 version)
- Fibromyalgia (2001 version)
- FACES Pain Scale (2001 version)
- Subcutaneous Lidocaine (2001 version)
- JAMA Pain Page (2001 version)

Cancer Care Flyers - 1 page flyers developed by Cancer Care, Inc. New York, NY

- “Does it Hurt?” Tips for managing Cancer Pain (1995 version)
- “It Doesn’t Have to Hurt”: Tips for managing Cancer Pain (1996 version)

W “How To Manage Your Pain: What you should know about it” - Montefiore Med. Ctr., New York (1995 version)

A 4-page guide that includes pain information and a questionnaire on pain management for patients, families, and health care providers.

W Patient Controlled Analgesia - Patient Instruction Guide - Bronx VA Medical Center, Bronx, New York (1995 version)

- Developed by Pain Mgmt. Clinical Specialist at the Bronx VAMC, as a patient education material for all patients on PCA.

W Patient Education Plan - Kaiser Permanente, Los Angeles, California (1995 version)

- Developed by Medical Care Program - Southern California Region. A checklist used for patient teaching and chart documentation. Includes key content for pain education.

W Patient Education Video and Booklet order form - Hospice of Henry Ford Health System, St. Clair Shores, MI (1996 version)

- The NHO Award of Excellence booklet and video, “Catch Your Pain Before It Catches You” is available for hospice patients to keep their hospice team informed and pain controlled.

W No More Pain booklet order form - Fox Chase Cancer Center, Philadelphia, PA (1996 version)

Order form to obtain this booklet for patient teaching regarding safe and effective control of cancer pain.

-
- W** Patient Medication Information - Fox Chase Cancer Center, Philadelphia, PA (1996 version)
- Patient handouts regarding use of medications. Eleven handouts include: Dilaudid tablets, Fentanyl patch, MS Contin, Morphine concentrate, Morphine Sulfate tablets or capsules, Oxycodone plus Acetaminophen, Oxycontin, Choline Magnesium Trisalicylate, Ibuprofen, Desipramine, Nortriptyline
-
- Guide for Patients and Families - Care of the Permanent Epidural Catheter - Fox Chase Cancer Center, Philadelphia, PA (1996 version)
- A 7-page guide with illustrations for patient and family education
-
- W** How to Get your Narcotic Prescription Filled - Fox Chase Cancer Center, Philadelphia, Pennsylvania (1996 version)
- A 2-page handout for patients with advice regarding obtaining opioid analgesics
-
- W** Continuous Pain Drug Therapy at Home with (INFUSAID) Internal Pump - Fox Chase Cancer Center, Philadelphia, PA (1996 version)
- A 4-page patient education material with illustrations.
-
- W** Pre-admission Testing Pain Management Patient Education Program - St. John Hospital & Medical Center, Detroit Michigan (1996 version)
- Pain management education brochure developed for mailing to patients who are scheduled for surgery
-
- W** Patient Rights and Responsibilities - Rockford Memorial Hospital, Rockford, Illinois (1996 version)
- This one page document describes the patient's rights and responsibilities to the commitment of excellence in pain management.
-
- W** Cancer Pain Can Be Relieved: A Guide for Patients and Families - Wisconsin Pain Initiative
- Six page booklet for patient education
-
- W** Patient Education book order forms packet
- Poetry of Pain: Poems of Truth, Acceptance and Hope for Those who Suffer Chronic Pain. A book written in 1996 by Linda Martinson contains 44 pages about pain, its neglect and under-treatment by professionals and through poetry, the adaptation of one patient to her painful plight.
 - Get Relief from Cancer Pain - American Cancer Society
- Booklet in 3 versions: English, Spanish and large print. The booklet is written to increase patient awareness of the importance of treating cancer pain. Booklets available through your local American Cancer Society office.
- Relieving Cancer Pain Management - Fred Hutchinson Cancer Research Center includes spiral booklet, videotape and a list of common problems with cancer patients and families in controlling pain management developed by Fred Hutchinson Cancer Research Center.
-
- “Taking Control of Your Pain” book order form- Massachusetts American Cancer

- W** Society
Booklets in different languages: Chinese, French, French-Creo, Italian, Portugese, Russian, Vietnamese, Laotian & Cambodian
-
- W** Easing Cancer Pain CD-ROM and Website information sheet - 1999 version
An interactive program designed to empower people with cancer who suffer from pain. It provides a wealth of resources to help them understand their pain and seek effective treatment. Website: <http://com.mtechlab.msu.edu/sites/cancerpain/>
-
- W** "Managing Cancer Pain: A Rural Perspective" order form - 1999 version
Video addresses common myths about cancer pain, barriers and how families face these challenges. Order form available on website at <http://www.vcpi.org/>
-
- W** Advanced Illness: Financial Guidance for Cancer Survivors and Their Families – American Cancer Society
An 18-page practical booklet covering important financial aspects related to cancer treatment, survivorship, as well as the impact on patient and family resources. Available on ACS website at <http://www.cancer.org> or call 1(800) ACS-2345.
-
- W** Coping Financially with the Loss of a Loved One: Financial Guidance for Families – American Cancer Society
A 34-page booklet addressing practical aspects of financial planning and decision-making after the loss of a loved one. Available on ACS website at <http://www.cancer.org> or call 1(800) ACS-2345.
-
- W** A Helping Handbook: When a Loved One is Critically Ill – Stephanie Waxman, RN
This 48 page Helping Handbook provides a private place to explore and express conflicting feelings and paves the way with inspirational poetry. Order at: <http://www.booksense.com/product/info.jsp?isbn=0970909209> (this will redirect to the website, enter your zip code to find your local bookstore)
-
- W** Understanding Cancer Pain/El Dolor Relacionado con el Cancer – National Institutes of Health, National Cancer Institute, September 2000
This informational material was produced collaboratively by the NCI and the Johns Hopkins Oncology Center, specifically for patients and their families. It is a 29-page booklet written at the 2nd-3rd grade reading level aimed at helping patients understand, assess, and communicate pain. It also includes a pain scale and diary for monitoring and recording cancer pain and a pain ruler for measuring pain. Topics covered include communication, gathering information, medicines, other methods to control pain, and additional information. It is also available in Spanish. This booklet is complementary and is available by calling NCI Cancer Information Service at 1-800-4-CANCER or visiting the web site at <http://cancer.gov/publications> by referencing NIH publication #P817 (English) or P696 (Spanish).
-
- W** Controlling Cancer Pain – National Institutes of Health, National Cancer Institute, September 2000.
A 12-minute video that reviews causes, treatment options and the importance of having

patients discuss pain symptoms with health professionals. It is intended for patients and their families. The video is complementary by contacting NCI Cancer Information Service at 1-800-4-CANCER or visiting the website at <http://cancer.gov/publications> by referencing NIH Publication #V814.

W Dispelling the Myths About Morphine.
Patient brochure. Information for safe and effective use of morphine in managing moderate to severe pain. Spanish version also available. The Resource Center of the American Alliance of Cancer Pain Initiatives, University of Wisconsin Medical School, 1300 University Avenue, Room 4720, Madison, WI 53706, (608) 262-0978, (608) 265-4014 FAX, Website: <http://www.wisc.edu/wcpi/>

W Eight Facts Everyone Should Know About Cancer Pain
Facts about cancer pain. Order form: The Resource Center of the American Alliance of Cancer Pain Initiatives, University of Wisconsin Medical School, 1300 University Avenue, Room 4720, Madison, WI 53706, (608) 262-0978, (608) 265-4014 Fax, Website: <http://www.wisc.edu/wcpi/publiced/publiced.htm>

W Get Relief from Cancer Pain order form
A simple patient education booklet that contains the essential facts about pain control. Booklet is downloadable from the website at http://oesi.nci.nih.gov/RELIEF/RELIEF_MAIN.htm

W Pain Control: A Guide for People with Cancer and their Families (#P258) order form
A guide for people with cancer and their families that contains detailed information about pain control. Booklet is downloadable from the website at <https://cissecure.nci.nih.gov/ncipubs/details.asp?pid=235> (this booklet replaces the former “Questions and Answers about Pain Control.”)

W Cancer Pain Education for Patients and the Public (CPEPP)
From 1997 to 2001 the City of Hope investigators (Betty Ferrell, Marcia Grant, and Gloria Juarez) conducted an education project funded by the National Cancer Institute. This project was designed to address the multiple opportunities for cancer pain education and to provide resources for successful implementation. Individual objectives addressed various forms of pain education, identifying barriers to pain management and describing cultural considerations in patient education for pain. The COH investigators are now making the key materials available on this website. The project materials on this site include outlines, Power Point presentations, handouts and a comprehensive bibliography for each module. Module I: Pain Management for Individual Patient Education; Module II-Cultural Considerations in Patient and Public Education. Module III – Pain Education provided through group settings; Module IV – Public Education for Pain Management; Module V – Telephone Education – Informal Systems; Module VI – The JCAHO Imperative: Improved Pain Management; Module VII – Professional Education as a Prerequisite to Patient Education: Involving Colleagues in Pain Education; Module VIII – Overcoming Institutional Barriers to Pain Education. An article summarizing this project was published in the *Journal of Pain and Symptom Management in 2002* [23(3): 7-8], which provides further detail regarding the training program.

W

Guide to Pain Control: Powerful Methods to Overcome Cancer Pain – 2001 version
A 384-page book published by the American Cancer Society written for people with cancer, their families, and caregivers. This comprehensive guide to understanding and managing cancer pain explains how cancer pain and its treatment affect the body, emotions, relationships, and outlook on life. ISBN #: 0-944235-33-6. Order through American Cancer Society website at <http://www.cancer.org>

D. Guidelines/Clinical Pathways

W

NCCN/ACS Cancer Pain: Treatment Guidelines for Patients – January, 2001
The National Comprehensive Cancer Network and the American Cancer Society collaboratively produced these treatment guidelines to provide patients and the general public with current cancer treatment information in understandable language. The information is based on the NCCN's Clinical Practice Guidelines and is intended to help patients dialogue with their physicians and healthcare staff about cancer pain. The Guidelines come in a 31-page booklet format and are available free of charge by contacting the NCCN at 1-888-909-NCCN or downloading them from the website at <http://www.nccn.org/>

E. Other Organizational Links

American Cancer Society	http://www.cancer.org
American Pain Foundation	http://www.painfoundation.org
National Cancer Institute	http://www.cancer.gov
The Patient Education Institute	http://www.patient-education.com

F. Key References

G. Position Statements/Standards

Pain in the Elderly

Section Description: This section includes Clinical Practice Guidelines on the Management of Pain in the Elderly from the American Geriatric Society and the American Medical Directors Association. Book order forms are available that address pain management in the elderly and in the long-term care setting.

A. City of Hope Publications

_____ Ferrell BA, Ferrell BR. (1990). "Pain in the nursing home." Journal of the American Geriatrics Society, 38: 409-414 - The focus of this study was to describe the scope of the problem of pain in a long term care facility. A sample of 92 subjects from a 311-bed multilevel teaching nursing home was interviewed and medical records were reviewed for pain problems and management strategies. Findings suggest pain is a major problem of the elderly in long term care facilities.

_____ Ferrell BR, Ferrell BA. (July/August 1990). "Easing the Pain." Geriatric Nursing, 4: 175-178 - This article challenges the misconceptions related to pain in the elderly. Pharmacologic and nonpharmacologic treatment modalities are discussed.

_____ McCaffery M, Ferrell BR. (1991). "Patient age - Does it affect your pain control decisions." Nursing, 21(9): 44-48 - This article describes a survey from 359 nurses, which explored the effect of patient age on nurses decisions regarding pain control. The survey demonstrated nurses are more willing to believe an elderly patients rating of pain but less likely to increase opioid analgesic dosing. Tips in overcoming misconceptions about pain in the elderly are included.

_____ Ferrell BA. (1991). "Pain management in elderly people" Journal of the American Geriatrics Society, 39: 64-73 - This article discusses pathophysiology of pain, evaluation of pain in the elderly, analgesic drug use in the elderly and nonpharmacologic pain relief methods.

_____ Ferrell BA, Ferrell BR, Rivera LM. (1995). "Pain in cognitively impaired nursing home patients." Journal of Pain and Symptom Management, 10(8): 591-598 - Reports findings from a study of 217 cognitively impaired residents of 10 nursing homes. The article discusses challenges in pain assessment in this population and recommendations for selection of pain assessment tools.

B. Recommended Books

_____ Pain in the Elderly book order form

W Published in 1996 by the International Association for the Study of Pain, 152 page softbound book outlining approaches to specific geriatric pain problems.

_____ Persistent Pain in Older Adults

W By Debra K. Weiner, MD, Keela Herr, PhD, RN, and Thomas E. Rudy, PhD, Editors. The goal of this book is to increase awareness of the complexity involved in caring for older adults with persistent pain and to provide practitioners with the tools to approach complex management issues. Springer Publishing Company. Website: <http://www.springerpub.com>

C. Educational Materials/Curriculum

Fast Facts-1 Minute Inservice
W Assessing Pain in the Cognitively Impaired

D. Guidelines/Clinical Pathways

W Clinical Practice Guidelines - The Management of Persistent Pain in Older Persons (2002)
- Clinical Practice Guidelines from the American Geriatrics Society. Download guidelines at <http://www.americangeriatrics.org/>

W Chronic Pain Management in the Long-Term Care Setting Clinical Practice Guideline (CPG) order form (1999 version) - Published by the American Medical Directors Association (AMDA)

This guideline outlines many of the myths and misperceptions about chronic pain caused by nonmalignant conditions and the barriers to effective pain management. The CPG also offers tips for overcoming these barriers. The guideline is directed toward the entire interdisciplinary team - as well as patients and their families - in order to achieve effective pain management. Visit the AMDA website: <http://www.amda.com/>

W Improving Pain Management in Long Term Care Settings book order form.

- Published in 1998 from the Medical College of Wisconsin as a resource guide for institutional change. Designed to assist staff member of facilities to improve pain management strategies for their residents. Order form downloadable at the Medical College of Wisconsin website at <http://www.mcw.edu/pallmed>

W Acute Pain Management in the Elderly guideline order form

This 83-page evidence-based guideline was developed from a synthesis of current evidence on managing acute pain in adults and in the elderly by investigators at the University of Iowa. Key areas highlighted are pain assessment and monitoring, patient education regarding pain management, pharmacological management of pain, and non-pharmacological management of pain. Also available is a set of eight Quick Reference Guides designed to help staff implement guideline recommendations into daily practice.

E. Other Organizational Links

AARP <http://www.aarp.org>
Administration on Aging <http://www.aoa.dhhs.gov>
Aging with Dignity <http://www.agingwithdignity.org>
American Geriatrics Society <http://www.americangeriatrics.org>
American Society on Aging <http://www.asaging.org>
Association for Gerontology in Higher Education <http://www.aghe.org>
The National Institute on Aging <http://www.nih.gov/nia/>

F. Key References

- N/A (please see note)
1. Herr, K. (2002). "Pain assessment in cognitively impaired older adults." American Journal of Nursing, 102(12): 65-68. (This publication is not available through the City of Hope Pain/Palliative Care Resource Center. Please contact the publisher to order this journal). Lippincott, Williams & Wilkins website: <http://www.lww.com> and search for AJN (American Journal of Nursing).

G. Position Statements/Standards

Quality Improvement

Section Description: This section includes medical review tools, strategic plans, performance and quality improvement packets, a manual for "building an institutional commitment to pain management", sample materials for quality improvement committees, and information on the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards for pain management.

A. City of Hope Publications

_____ Ferrell BR, McCaffery M, Ropchan R. (1992). "Pain management as a clinical challenge for nursing administration." Nursing Outlook, 40(6): 263-268 - This article cites numerous studies on the prevalence of pain and the lack of knowledge of nurses in treating pain. Four challenges for nurse administrators are identified in improving the quality of pain management.

_____ Ferrell BR. (1993). "The challenge for leadership in the national agenda for relief of cancer pain." Commentary, Journal of the National Cancer Institute, 85(13): 1034-1037 - The focus of the article suggests a leadership role by Cancer Centers in committing to four critical areas of pain management. These include establishing standards for 1) knowledge and attitudes of health care providers, 2) assessment of pain, 3) patient education related to pain, and 4) development of pain services.

_____ Miaskowski C, Jacox A, Ferrell B, et al. (1994). "Clinical practice guideline development: A historical perspective and nursing implications." Oncology Nursing Forum. 21(6): 1067-1069 - The purpose of this article is to provide oncology nurses with information about the Agency for Health Care Policy and Research (AHRQ), the process of clinical guideline development, and the implications for oncology nursing practice.

_____ Ferrell BR, Jacox A, Miaskowski C, Paice JA, Hester NO. (1994). "Cancer guidelines: Now that we have them, what do we do?" Oncology Nursing Forum, 21(7): 1229-1238 - This article emphasizes 27 specific strategies for use in addressing pain management while implementing cancer pain guidelines developed by the Agency for Health Care Policy and Research (AHRQ).

_____ Ferrell BR. (April/May 1994). "An institutional commitment to pain management." American Pain Society Bulletin: 16-20 - Successful pain management requires involvement of individuals at all levels of the organization. Approaches to obtaining this goal include documenting pain, making pain visible, establishing standard of care, redesigning the team, educating staff, educating patients, educating the public, involving institutions in regulatory issues, and recognizing the cost of failure to treat pain.

Ferrell BR, Dean GE, Grant M, Coluzzi P. (1995). "An institutional commitment to pain management." Journal of Clinical Oncology, 13(9): 2158-2165 - Shares the development, implementation, and evaluation of this program which is based on the philosophy of organizational influence on pain management.

Ferrell BR, Whedon M, Rollins B. (1995). "Pain and quality assessment/improvement." Journal of Nursing Care Quality, 2(3): 69-85 - This article reviews essential components of the QA process in pain management and shares experiences from institutions.

Grant M, Rivera LM, Alisangco J, Francisco L. (1999). "Improving cancer pain management using a performance improvement framework." Journal of Nursing Care Quality. 13(4): 60-72 - This article describes the development, implementation and evaluation of a pain education program designed to provide clinical nurses with the knowledge necessary to use appropriate pain management techniques.

B. Recommended Books

Handbook and manual packet order forms

-
- W**
- "Building An Institutional Commitment to Pain Management" manual order form - Wisconsin Cancer Pain Initiative, Madison, WI. This resource is the "how to" manual designed to make pain management a reality in a clinical setting – 2000 version
 - "Handbook of Cancer Pain Management" 5th Edition order form- The Medical College of Wisconsin and University of Wisconsin Medical School, Madison, WI. This manual is to provide health care professionals with information about diagnosis and management of cancer-related pain – 1997 version

C. Educational Materials/Curriculum

Action Plan - Long Term Care - Medical College of Wisconsin, Milwaukee, WI.

-
- W**
- This action plan is a format for an institution to implement a strategic plan in establishing a pain management program – 1996 version

D. Guidelines/Clinical Pathways

Medical Record Audit Form - U. of Wisconsin Hospital & Clinics, Madison – 1999 version

-
- W**
- Comprehensive audit tool to review documentation of pain assessment, analgesic prescribing and administration practices.

Pain Management Program/Strategic Plan - Dominican Santa Cruz Hospital, Santa Cruz, California – 1995 version

-
- W**
- The Strategic Plan includes a 16 page packet describing a pain management program and strategic plan. A vision statement, basic assumptions, targets, goals, and strategies for implementation are outlined

Pain Care Packet - The Chambersburg Hospital, Chambersburg, Pennsylvania – 1995 version

-
- W**
- Includes a 4 page packet containing a 9 item Pain Questionnaire for use after discharge, a 7 item Pain Service Outcome Survey and an 11 item outline of "Rights of the Patient"

and Responsibility of the Physician”

W Performance Improvement Plan - Integris/Baptist Medical Center, Troy and Dollie Smith Cancer Center, Oklahoma City, Oklahoma – 1996 version
The Performance Improvement Plan was designed to implement the American Pain Society’s Quality Assurance Standards and to monitor outcomes

W Patient Questionnaire on Pain Management - Willamette Falls Hospital, Oregon City, Oregon – 1996 version
A simple questionnaire used to assess patient satisfaction with pain after hospitalization. The tool is formatted for easy use as a mailed survey

W Proposal: An Institutional Commitment to Pain Management - U. of Wisconsin Hospitals & Clinics, Madison, WI – 1996 version
A 1-page proposal for establishing a quality improvement program to improve pain management

W Institutional Needs Assessment – Wisconsin Cancer Pain Initiative, Madison, Wisconsin – 1997 version

W Sample Materials for Use in Developing a Quality Improvement Committee - Wisconsin Cancer Pain Initiative, Madison, Wisconsin
- Sample Invitation Letter, Mission Statement and Meeting Agendas – 1996 version
- Development of Quality Improvement Plan Worksheet – 1996 version

W Text for ‘Transparencies’ - Wisconsin Pain Initiative, Madison, Wisconsin – 1996 version
- Text for transparencies for use in presentations related to pain and quality assurance (includes 19 pages ready to make transparencies)

W Quality Assurance Packet - Saint Luke’s-Shawnee Mission Health System, Shawnee Mission, Kansas - 1998 version
- Commitment to Cancer Pain Management Statement
- Patient Rating Guide
- Patient Outcome Questionnaire
- Chart Audit Tool
- Pain Assessment Flowsheet
- Palliative Care Protocol
- MS Drip Protocol
- Care of Patient Experiencing Cancer Related Pain

W Joint Commission on Accreditation of Healthcare Organizations Revised Pain Management Standards, 2000
Revised pain standards for Hospitals published by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). Website: <http://www.jcaho.org/> (at website search for standards revisions for 2002)

Joint Commission on Accreditation of Healthcare Organizations (JCAHO) packet – Southern California Cancer Pain Initiative (SCCPI)

The Southern California Cancer Pain Initiative (SCCPI) has developed a Resource Packet of a compilation of materials to serve as a resource for JCAHO accredited institutions to become compliant with the new JCAHO pain standards. This 3-inch binder of materials addresses many aspects of the standards and several facets of pain treatment. Order forms are available through the SCCPI website at <http://sccpi.coh.org>, by contacting the SCCPI office at (626) 359-8111 ext. 63202, or e-mail: sccpi@coh.org.

E. Other Organizational Links

Institute for Healthcare Improvement <http://www.ihl.org>

Joint Commission on Accreditation of Healthcare Organizations <http://www.jcaho.org>

F. Key References

G. Position Statements/Standards

Ethics

Section Description: This section includes materials related to ethical issues and end of life care in pain management, decision making and suffering.

A. City of Hope Publications

Johnston-Taylor E, Ferrell BR, Grant M, Cheyney L. (1993). "Managing cancer pain at home: The decisions and ethical conflicts of patients, family caregivers, and homecare nurses." Oncology Nursing Forum, 20(6): 919-927 - This article identifies the content of decision making and ethical conflict among patients with cancer related pain, their family caregivers, and home health nurses. Data obtained from this sample identified subjects' decision making and conflict centered around use of medication for pain relief.

Ferrell BR, Johnston-Taylor E, Sattler GR, Fowler M, Cheyney BL. (1993). "Searching for the meaning of pain." Cancer Practice, 1(3): 185-194 - This study explores the meaning of pain from data collected and analyzed using qualitative methods with the assistance of a multidisciplinary team of nurses and theologians. A model of the process of seeking meaning for pain is offered through interview data from patients, family caregivers, and nurses.

Ferrell BR, Dean GE. (1994). "Ethical issues in pain management at home." Journal of Palliative Care, 10(3): 67-72 - This article discusses the ethical issues surrounding pain management at home such as decision making and the family experience with pain. Examples of descriptions of pain, caregiver roles, and patients' decisions and conflicts are provided.

Ersek M, Ferrell BR. (1994). "Providing relief from cancer pain by assisting in the search for meaning." Journal of Palliative Care, 10(4): 15-22 - This article provides an overview of the literature and an integrated approach to assisting patients and their family caregivers with the meaning-making process associated with cancer pain.

Ferrell BR, Dean G. (1995). "The meaning of cancer pain." Seminars in Oncology

Nursing, 11(1): 17-22 - This article discusses the meaning of pain and suffering experienced by both patients and families and provides case examples and analysis of the search for meaning in cancer pain.

W

Text on Suffering (1996) edited by Betty Ferrell with chapters addressing various dimensions of suffering in AIDS, cancer, pediatrics. Order form provided only.

Borneman T, Ferrell BR. (August 1996). "Ethical issues in pain management." Clinics in Geriatric Medicine, 12(3): 615-628 - This article provides an overview of common ethical issues in pain management, especially in the elderly population, with discussion of the moral issues of euthanasia and assisted suicide.

Ferrell BR, Rivera LM. (1995). "Nursing perspectives on assisted suicide and euthanasia." Journal of Pharmaceutical Care in Pain & Symptom Control, 3(3/4): 55-66 - This article addresses the challenge nurses are faced with in providing compassionate care to terminally ill patients and their families.

Ferrell BR. (1996/1997). "The moral imperative of pain management." Symptom Control in Cancer Patients. American Nurses Association Center for Ethics and Human Rights, 5(2): 4-5 - This article addresses the undertreatment of pain and the responsibility for relief by health professionals.

Ferrell BR. (1997). "The role of ethics committees in responding to the moral outrage of unrelieved pain." Bioethics Forum, 13(3): 11-16 - This article addresses ten strategies for involvement of ethics committees in improved pain management.

Ferrell BR, Novy D, Sullivan M, Banja J, Dubois M, Gitlin M, Hamaty D, Lebovits A, Lipman A, Lippe P and Livovich J. (2001). "Ethical Dilemmas in Pain Management." The Journal of Pain, 2(3): 171-180 - This study surveyed the membership of the American Pain Society and the American Academy of Pain Medicine to determine their beliefs about ethical dilemmas in pain management practice.

B. Recommended Books

Palliative Care Ethics: A Companion for all specialties, 2nd edition

W

This book has been written by a clinician and a teacher and writer of health care ethics to provide all those who care for the terminally ill - doctors, nurses, social workers, physiotherapists, clergy and other carers - with the concepts and principles to assist them in difficult decisions. Oxford University Press. ISBN: 0192630687. Website: <http://oup-usa.org>

C. Educational Materials/ Curriculum

D. Guidelines/ Clinical Pathways

E. Other Organizational Links

American Society for Bioethics and Humanities

<http://www.asbh.org>

American Society of Law, Medicine and Ethics

<http://www.aslme.org>

American Society of Pain Management Nurses (ASPMN)

<http://www.aspmn.org>

Center for Ethics in Health Care – Oregon Health Sciences University	http://www.ohsu.edu/ethics/
Center for Bioethics and Human Dignity	http://www.cbhd.org
Centre for Bioethics	http://www.Ircm.qc.ca/bioethique/english
Cleveland Clinic, Department of Bioethics	http://www.clevelandclinic.org/education/bioethics/
European Ethics	http://www.masterbioethics.org/
Hastings Center	http://www.thehastingscenter.org/
Midwest Bioethics Center	http://www.midbio.org
National Bioethics Advisory Commission	<a href="http://www.nih.gov/sigs/bioethics/wi<thinnih.html">thinnih.html
University of Minnesota Center for Bioethics	http://www.bioethics.umn.edu/education/

F. *Key References*

G. *Position Statements/Standards* (see **XI. End of Life/Palliative Care, G. Position Statements/Standards**)

Family/Home Care

Section Description: This section includes publications regarding the experiences of family members in caring for a loved one in pain.

A. *City of Hope Publications*

_____ Ferrell BR, Rhiner M, Cohen MZ, and Grant M. (1991). "Pain as a metaphor for illness. Part I: Impact of cancer pain on family caregivers." *Oncology Nursing Forum*, 18(8): 1303-1309 - This two-part article contributes to the Pain-QOL model by describing the social concern domain. A sample of 85 primary family caregivers of patients with cancer pain was obtained from three settings. Themes were identified with regard to the families' experience of pain.

_____ Ferrell BR, Cohen MZ, Rhiner M, Rozek A. (1991). "Pain as a metaphor for illness. Part II: Family caregivers' management of pain." *Oncology Nursing Forum*, 18(8): 1315-1321. - This article focuses on seven themes identified by caregivers of patients with cancer pain related to aspects of medication administration, nondrug interventions, and support from doctors and nurses.

_____ Ferrell BR, Rhiner M, Rivera LM. (1993). "Development and evaluation of the family pain questionnaire." *Journal of Psychosocial Oncology*, 10(4): 21-35. - This article presents the Family Pain Questionnaire (FPQ) instrument used to obtain data on caregiver perspectives of pain management.

_____ Ferrell BR, Grant M, Chan J, Ahn C, Ferrell BA. (1995). "The impact of cancer pain education on family caregivers of elderly patients." *Oncology Nursing Forum*, 22(8): 1211-1218 - This article examines the impact of pain education on family members providing home care to elderly patients with cancer.

_____ Juarez G, Ferrell BR. (1996). "Family and caregiver involvement in pain management."

Clinics in Geriatric Medicine, 12(3): 531-547 - This article discusses the importance of chronic cancer pain management in the elderly population including an overview of family involvement, and family education.

_____ Ferrell BR, Grant M, Borneman T, Juarez G, terVeer A. (1999). "Family caregiving in Cancer Pain Management." Journal of Palliative Medicine, 2(2): 185-195 - This article describes the study which shares the experience of pain management from the perspective of family caregivers of patients with cancer amidst the healthcare environment. The article also includes data regarding costs of caregiving and pain management at home.

_____ Ferrell BR. (May/June 1998). "Pain management at home." Coping, (May/June): 40-41 - This article focuses on pain education as the common symptom in cancer throughout all stages of the illness.

_____ Ferrell BR, Borneman T, Juarez G. (1998). "Integration of pain education in home care." Journal of Palliative Care, 14(3): 62-68. - Focus on the needs of home care patients and issues surrounding the integration of pain education into routine home care.

_____ Ferrell BR, Juarez G, Borneman T, ter Veer Anna. (October-December, 1999). "Outcomes of Pain Education in Community Home Care." Journal of Hospice and Palliative Nursing, 1(4): 141-150 - Reports findings of a study of 149 cancer patients receiving pain education through home care agencies.

_____ Ferrell BR (2001). "Pain Observed: The Experience of Pain from the Family Caregiver's Perspective." Clinics in Geriatric Medicine, 17(3): 595-609 – Summary of program of research regarding family caregivers and pain management including research methods and clinical implications.

_____ Borneman T, Stahl C, Ferrell BR, Smith D (2002). "The Concept of Hope in Family Caregivers of Cancer Patients at Home." Journal of Hospice and Palliative Nursing, 4(1): 21-33 – this article is intended to provide descriptive data regarding hope and sources that promote hope in family caregivers of cancer patients at home.

B. Recommended Books

_____ Handbook for Mortals book order form

W Guidance for people facing serious illness by Joanne Lynn, M.D. and Joan Harrold, M.D. Order form available at <http://www.abcd-caring.org/>

_____ Be Prepared by David S. Landay order form

W Order book through website at <http://www.be-prepared.com/>

_____ Fading Away: The Experience of Transition in Families with Terminal Illness

W This book comes out of an in-depth, qualitative study of the experiences of twenty-three families in which one parent was dying of cancer. The study attempted to better understand the impact of terminal illness on the entire family system and sought to develop a theoretical framework that would guide the assessment of and services to

such families. As a result of interviews with patients, spouses and their adult children over three phases of the study, the process of "fading away" was identified and conceptualized in terms of various phases which contributed to this process. Baywood Publishing Company, Inc. ISBN: 0-89503-127-2. Website: <http://www.baywood.com>

C. Educational Materials/ Curriculum

D. Guidelines/ Clinical Pathways

E. Other Organizational Links

American Pain Foundation

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

Caregiver Network

<http://www.caregiver.on.ca/index.htm>

Caregiver.com

|

<http://www.caregiver.com>

Caregiver.org

<http://www.caregiver.org>

Caregiver Resource Directory

http://www.stoppain.org/caregivers/Resource_form.html

Caregiver Survival Resources

<http://www.caregiver911.com>

Careguide.com

<http://www.careguide.com>

National Alliance for Caregiving

<http://www.caregiving.com>

National Family Caregivers Association

<http://www.nfcacares.org>

F. Key References

G. Position Statements/ Standards

Pharmacology/Policies and Procedures

Section Description: Includes pain management reference cards, algorithm packets, along with flowsheets to record pain assessment and management as well as meperidine usage guidelines

For more information see III. Patient Education

A. City of Hope Publications

McCaffery M, Martin L, Ferrell BR. (1992). "Analgesic administration via rectum or stoma." Journal of ET Nursing, 19: 114-121 - This article discusses rectal and stomal routes for administering analgesics as alternatives to invasive parenteral routes when a patient is unable to take medication by mouth.

Ferrell BR, Cronin C, Warfield C. (1992). "The role of patient-controlled analgesia in the management of cancer pain." Journal of Pain and Symptom Management, 7(3): 149-154 - This paper reviews the literature related to patient controlled analgesia (PCA) use in chronic cancer pain. Appropriate and inappropriate utilization of PCA is discussed as well as professional issues in future use of PCA.

Ferrell BR. (October 1991). "Managing pain with long-acting morphine." Nursing91, 21(10): 34-40 - This article includes information related to administration of long acting morphine, and describes specific methods of switching from short acting to long acting analgesic. Management of adverse reactions and rescue dosing are also described.

McCaffery M, Ferrell BR. (1996). "Ethical issues in the use of placebos in cancer pain

management.” *Oncology Nursing Forum*, 23(10): 1587-1593 - This article identifies and corrects misconceptions about placebos, and discusses the ethical issues related to administering placebos for patients experiencing cancer pain.

Ferrell BR, McCaffery M. (1997). “Nurses’ knowledge about equianalgesia and opioid dosing.” *Cancer Nursing*, 20(3): 201-212 - This article states the results from a study which evaluated nurses knowledge regarding three methods of analgesic delivery that have become common in clinical practice.

Hitchcock LS, Ferrell BR, McCaffery M. (1994). "The experience of chronic nonmalignant pain." *Journal of Pain and Symptom Management*, 9: 312-318 - This article reports results of a survey from 204 persons with chronic nonmalignant pain who were members of a self help organization. A 46-item questionnaire elicited responses about pain intensity, types of pain, medications prescribed, medications not prescribed but taken for pain, and a list of 10 problems with non malignant pain management.

Ferrell BR, Juarez G, Borneman T. (1999). “Use of routine and breakthrough analgesia in home care.” *Oncology Nursing Forum*, 26(10): 1655-1661 - This article reviews principles of assessing and treating breakthrough pain and deficiencies in current approaches.

B. Recommended Books

W Pain: Clinical Manual 2nd Edition by McCaffery & Pasero, 1999 book order form - this manual is an invaluable guide to an interdisciplinary approach in the care of patients with pain. ISBN #: 0-8151-5609-X (29563). Visit <http://www.mosby.com> to order. (enter ISBN # or search for pain on website to find this item)

C. Educational Materials/ Curriculum

Equianalgesic Chart order form

W Laminated Equianalgesic pocket card – Southern California Cancer Pain Initiative (SCCPI), 2001 version. Southern California Cancer Pain Initiative, c/o City of Hope National Medical Center, 1500 East Duarte Road, Duarte, CA 91010. Phone: 626-359-8111 X63202. Website: <http://sccpi.coh.org>

Pain Management Flowsheet Packet

St. John Hospital/Medical Center, Detroit, MI – 1995 version

This 1-page flowsheet provides healthcare providers documentation for analgesic orders and other pain data. Includes pain rating scales.

U. of Wisconsin Hospital & Clinics, Madison, WI – 1996 version

This flowsheet is used to record pain assessment and management information.

City of Hope, Duarte, CA – 1995 version

Flowsheet for PCA and Epidural Analgesia

Algorithm Packet

W - Symptom Management Algorithms for Palliative Care – **book order form** 1999 version – Providence Yakima Medical Center Pharmacy and Hospice of Yakima, Washington. Order form for this 190-page booklet which was awarded the Abbott Laboratories National Pharmacy Award for hospice and home care – 1999 version.

Website: <http://www.intelli-card.com>

- Cancer Pain Algorithm Reference Guide – order form 1999 version – Du Pen, Inc., Washington. – Description and ordering information for a reference guide that provides an overview of the pain algorithm. Website: <http://www.painconsult.com/>

W

Cancer Pain Role Model Program Case Studies and Faculty Guides – Wisconsin Pain Initiative

Includes 7 case studies and faculty guides for each to use in teaching basic pharmacology principles related to pain – 1996 version.

W

Meperidine-Drug Usage Evaluation Packet

St. Francis Medical Center Cape Girardeau, Missouri – 1995 version. Presents St. Francis Medical Center’s policy and procedure on the administration of meperidine. References included.

University of Wisconsin Hospital and Clinics – 1999 version. Policy that states the appropriate indications, dosage and precautions on the use of meperidine (Demerol) and a meperidine guideline audit form from the University of Wisconsin Hospital and Clinics.

University of Pittsburgh Medical Center Presbyterian (UPMCP) – 1999 version. Meperidine and Naloxone Guidelines developed and implemented by the multidisciplinary team.

W

Studies and Faculty Guides – Wisconsin Cancer Pain Initiative

Includes 5 case studies and faculty guides for each to use in teaching basic pharmacology principles related to pain – 1996 version

W

Care & Monitoring of Patients requiring Local Anesthesia and/or Sedation for Surgery & Invasive or Diagnostic Procedures - Department of the Army, Tripler Army Medical Center, Tripler, Hawaii

1997 version of a 38-page packet including policies and forms to guide care of patients requiring conscious sedation

W

Patient Contracts

A packet written by Margo McCaffery including a discussion of the use of contracts with patients receiving opioids.

W

Fast Facts – 1 Minute and 5 Minute Inservices

Opioid Dose Escalation

Converting To/From Transdermal Fentanyl

Sublingual Morphine

Balanced Analgesia or Multimodal Therapy

What is Neuropathic Pain?

Constipation

Transitional Analgesia

Patient Controlled Epidural Analgesia (PCEA)

Management of Post-operative Pain in Patients on Chronic Opioid Therapy

PRN Range Analgesic Orders

Methadone (Dolophine™)

Opioid Withdrawal

D. Guidelines/Clinical Pathways

Achieving Balance in Federal & State Pain Policy – 2000 version

W Evaluation guide presents a framework that has been developed by the Pain & Policy Studies Group (PPSG) to understand and to evaluate policies at the federal and state level. The Evaluation Guide is available on the PPSG website at <http://www.medsch.wisc.edu/painpolicy> and hard copies may be obtained by contacting the PPSG.

City of Hope Policies Duarte, CA (\$5.00/per copy) – 1995 version

Introduction, Procedural Related Pain, CADD PCA Drug Delivery, Continuous Infusion of Opioids, Epidural Administration of Opioids, Surgical Pain Management, Nausea, Constipation, Recommendations for Narcan Use, Assessment Tools, Patient Controlled Analgesia Flow Sheet, Discontinuation of Opioids/Withdrawal

Pain Management Resource Manual - Virginia Commonwealth University, Richmond (\$5.00/per copy) – 1999 version

W - Continuous Infusions, PCA via Epidural Catheters, Pediatric Patients Receiving Epidural Analgesia, Narcotic Control, Nursing Care of the Patient Receiving TENS, Subcutaneous Infusion/PCA, Application and Destruction of Fentanyl Transdermal Patches and other procedures.

Placebo Usage Packet (\$5.00/Packet)

Ferrell, BR, McCaffery, M. "Current Placebo Practice and Policy." *ASPMN Pathways*, 1996; Winter Issue, 11-14.

McCaffery M, Ferrell BR, Turner M. "Ethical Issues in the Use of Placebos in Cancer Pain Management." *Oncology Nursing Forum*, 1996; 3(10):1587-1593.

- Guest Editorial - Pain and Placebos: Ethical and Professional Issues
Orthopaedic Nursing, Sept./Oct. 1997; 5(16):8-12.

W Placebo Bibliography

W ASPMN Position Statement on the Use of Placebos for Pain Management

Pain Management Packet - Harrison Hospital, Bremerton, Washington – 1996 version

W Materials produced by the Pain Management Task Force including the Patient Admission Record, Morphine Continuous Infusion Standing Orders, Epidural Catheter Standing Orders, PCA Physician Order Sheet, Description of the Pain Task Force and Nursing Division Patient Care Guidelines

Policy and Procedure Packet – 1996 version

W - Continuous Subcutaneous Opioid Infusion - U. of Wisconsin, Madison, WI. This policy describes the initiation and maintenance of a continuous subcutaneous opioid infusion
Standard of Nursing Practice: Opiate Infusions - Fox Chase Cancer Center, Philadelphia, PA. This nursing practice governs the policy and procedures of opiate infusions

Conscious Sedation/Analgesia Packet

- W** - Adults Policy and Procedure. Developed by Christine L. Pasero, RN, BSN, MHSAC, a Pain Management Consultant, this guideline is intended to assist in developing a policy and procedure to help insure safe administration of conscious sedation – 1996 version
- City of Hope Policy and Procedure for Conscious Sedation for Invasive and Diagnostic Procedures – 1997 version

W The Use of Opioids for the Treatment of Chronic Pain – 1997 version
American Academy of Pain Medicine and American Pain Society policy.

W Definitions Related to the Use of Opioids for the Treatment of Pain – 2001 version

- American Academy of Pain Medicine, American Pain Society, and American Society of Addiction Medicine policy. Website:
<http://www.painmed.org/productpub/statements/pdfs/definition.pdf>

W Policy - California Board of Registered Nursing – 1997 version

- Pain Management Policy and Curriculum Guidelines for Pain Management Content

Patient Care Guidelines Packet – Vancouver Hospital & Health Sciences Centre, Vancouver, British Columbia – 1999 version

Coping with Pain

Care & Management of Patient with Chronic Cancer Pain

Conscious Sedation Guidelines for Nursing Management of Children in the Emergency Department

Pain: Conscious Sedation for Procedural Pain (Adults)

Pain: Conscious Infusion of Low Dose Ketamine, Nursing Management of the Patient

Patient Controlled Epidural Analgesia – What is an Epidural?

Pain: Epidural Catheter, Nursing Management of the Patient

Epidural catheter Systems: Tubing, Filter and Cap Change

Post-operative Infusion of Continuous Regional Analgesia (PICRA): Nursing Management of the Patient

Pain: Intrathecal Injection or Infusion, Nursing Management of the Patient

Pain: Nitrous Oxide (Entonox Gas): Use of Patient Controlled Analgesia

Pain: Patient Controlled Analgesia (PCA)

Care and Management of the Patient undergoing a Stellate Nerve Block (Pre-Post)

Therapeutic Touch – (Patient Information)

Therapeutic Touch

Pain: Visual Analogues in English, Chinese, Korean, Punjabi and Vietnamese

W Health Information Sheets on Pain Procedures – St. Vincent Hospital and Health Center, Billings, MT – 2000 version

Facet Joint Injection

Lumbar Sympathetic Block

Stellate Ganglion Injection

Intrathecal Pump Implant (Spinal Morphine Pump)

Radio Frequency Lesioning

Epidural Steroid Injection
Dorsal Column Stimulator (DCS) or Spinal Cord Stimulator (SCS)
Epidurolysis (Racz Procedure)
Sacro-Iliac Joint Injection

W Packet of Clinical Pathway Examples
Cancer Pain Management Critical Pathway – University of Wisconsin Hospital & Clinics, Madison, WI. Developed by the Coordinated Care Committee, this multidisciplinary chart documentation form for hospitalization (1999 version).

W Packet of Clinical Pathway Examples - Via Christi Regional Medical Center-St. Francis Campus, Wichita, KS – 1996 version

- Clinical Pathway for Acute Pain Management (1996 version) – Adult
This one-page clinical pathway flow chart for acute pain management covers a 5-day hospital admission.
- Clinical Pathway for Acute Pain Management (1996 version) – Pediatric
This one-page clinical pathway flow chart for acute pain management for pediatric use covers a 5-day hospital admission.
- Clinical Pathway for Collaborative Care (1996 version): Acute Pain Management
This one-page quality assurance documentation form is for use with the clinical pathway for collaborative care - acute pain management.

W Pain Management Standards

- Nursing Responsibilities for Pain Management -U. of Wisconsin Hospital & Clinics, Madison, WI - Statement on pain management, nursing competency for pain management, algorithm for reporting unrelieved pain, and a brief synopsis and post-test on principles of pain management (1999 version)
Mission Statement for Pain Management Center - Fox Chase Cancer Center, Philadelphia, PA (1996 version) - This brief mission statement emphasizes the interdisciplinary approach to the total treatment of pain.

Pain Algorithm Information - Memorial Sloan-Kettering Cancer Center, New York, NY - 1996 version
A 2-page flowsheet developed by the hospital Algorithm Committee for pain management.

W The Standard of Care for the Patient with Pain - Memorial Sloan-Kettering Cancer Center, New York, NY – 1996 version
This standard of care for pain treatment includes the areas of general outcomes, assessment, interventions and nursing diagnosis

W Agency for Healthcare Research and Quality (AHRQ) Pain Guidelines: formerly AHCPR (Agency for Health Care Policy and Research):
Acute Pain Guidelines:
Acute Pain Guidelines from AHRQ (Web address: <http://www.AHRQ.gov/>):
Acute Pain Management in Adults: Operative Procedures, Quick Reference Guide for Clinicians No. 1a, AHRQ Pub No. 92-0019, February, 1993.
Acute Pain Management in Infants, Children, and Adolescents: Operative Procedures,

Quick Reference Guide for Clinicians No. 1b, AHRQ Pub No. 92-0020, February, 1993.
Pain Control After Surgery, A Patient's Guide, Consumer Guideline Number 1, AHRQ
Pub No. 92-0021, February, 1993. Spanish version, AHRQ Pub No. 92-0068,
September, 1992.

Acute Pain Management: Operative or Medical Procedures and Trauma, Clinical
Practice Guideline 1, AHRQ Pub No. 92-0032, February, 1992.

Cancer Pain Guidelines from AHRQ (web address: <http://www.AHRQ.gov/>):

Management of Cancer Pain, Clinical Guideline Number 9, AHRQ Pub. No. 94-0592,
March, 1994.

Management of Cancer Pain: Adults, Quick Reference Guide for Clinicians Number 9,
AHRQ Pub. No. 94-0593.

Managing Cancer Pain, Consumer Guide Number 9, AHRQ Pub. No. 94-0595, March,
1994. Spanish version, AHRQ Pub. No. 94-0596, March 1994.

To order: AHRQ Publications Clearinghouse, 2101 East Jefferson Street Rockville, MD
20852, (800) 358-9295, Website: <http://www.AHRQ.gov> or U.S. Government Printing
Office, GPO Order Desk, (202) 512-1800

W

Practice Parameters for Systematic IV Analgesia and Sedation for Adult Patients in the
ICU: Sustained Neuromuscular Blockade in the Adult Critically Ill Patient

Practice parameters developed by a task force of the American College of Critical Care
Medicine (ACCM) & approved by ACCM Board of Regents and the Society of Critical
Care Medicine. To order: Society of Critical Care Medicine, 8101 East Kaiser Blvd.,
Suite 300, Anaheim, CA 92808-2259, (714) 282-6056, (714) 282-6050 Fax, Website:
<http://www.sccm.org>

W

Protocols for Practice: Pain Management in the Acutely Ill (Author: Julie Stanik-Hoff),
1998.

Part of a series 6 books of Protocols for Practice: Creating a Healing Environment. To
order: American Association of Critical Care Nurses, 101 Columbia, Aliso Viejo, CA
92656, (800) 899-2226, (949) 362-2000 Fax, Website: <http://www.aacn.org>, E-mail:
aacninfo@aacn.org

W

Reflex Sympathetic Dystrophy/Complex Regional Pain Syndrome – 2nd edition, updated
2002

Download guidelines from Reflex Sympathetic Dystrophy Syndrome Association
(RSDSA) website at <http://www.rsds.org>

W

Guideline for the Management of Pain in Osteoarthritis, Rheumatoid Arthritis, and
Juvenile Chronic Arthritis – American Pain Society, Volume 2, 2002.

Order from American Pain Society at <http://www.ampainsoc.org/>

W

Guideline for the Management of Acute Pain in Sickle-Cell Disease – American Pain
Society, 2001.

Order from American Pain Society at <http://www.ampainsoc.org>

W

Building An Institutional Commitment to Pain Management order form - Wisconsin
Cancer Pain Initiative, Madison, WI. (see full description under V. Quality
Improvement, B. Recommended Books, Item 1)

W

Standards of Clinical Nursing Practice for Pain Management – American Society of Pain Management Nurses
Order from American Society of Pain Management Nurses at <http://www.aspmn.org/>

W

Self-Directed Learning Program: Epidural Analgesia for Acute Pain Management – American Society of Pain Management Nurses
Receive 4.6 contact hours for completing this program from the American Society of Pain Management Nurses. Order from website: <http://www.aspmn.org/>

E. Other Organizations Links

American Pain Society <http://www.ampainsoc.org/>
Agency for Healthcare Research and Quality <http://www.AHRQ.gov/>
Cynergy Group <http://www.cynergygroup.com>
(equi-analgesic calculator)
Institute Fulfillment Center <http://www.institutedc.org/>
(an A-Z listing of all the drugs that are available through patient assistance programs)

Johns Hopkins Opioid Program <http://www.hopkinskimmelcancercenter.org/specialtycenters/hop.cfm>
University of Wisconsin Pain & Policy Studies Group <http://www.medsch.wisc.edu/painpolicy/>

F. Key References

G. Position Statements/Standards

W

American Nurses Association Position Statement
Endorsement of Position Statement on the Role of the Registered Nurse (RN) in the Management of Patients Receiving IV Conscious Sedation for Short-Term Therapeutic, Diagnostic, or Surgical Procedures, 1991 version, view on American Nurses Association website at <http://www.nursingworld.org/>

W

California Board of Registered Nursing Position Statement – 1995 version
It is within the scope of practice of registered nurses to administer medications for the purpose of induction of conscious sedation for short-term therapeutic, diagnostic or surgical procedures. Download at <http://www.rn.ca.gov>

Pediatrics

Section Description: This section includes patient and family educational books and pamphlets as well as policy statements from professional organizations on pediatric pain management. Bibliographies on neonates and pediatric reference lists and resources are also included. Additional assessment tools for pediatrics can be found under the Research Instruments Section XVI in this Index.

A. City of Hope Publications

Shapiro BS, Ferrell BR. (1992). "Pain in children and the frail elderly: Similarities and implications." APS Bulletin – American Pain Society, (October/November): 11-13 - This article explores similarities of pain in children and the frail elderly. Loss of social power as a result of their helplessness predisposes them to neglect. The authors identify a

paucity of research in the area resulting in inappropriate treatment and the invisibility of the problem.

Ferrell BR, Rhiner M, Shapiro B, Dierkes M. (1994). "The experience of pediatric cancer pain. Part I: Impact of pain on the family." *Journal of Pediatric Nursing*, 9(6): 368-379 - Part I of this 2-part article explores family caregivers' descriptions of their child's cancer pain. Qualitative data from 31 family caregivers is included in tables by key themes describing the child's pain and family impact.

Rhiner M, Ferrell BR, Shapiro B, Dierkes M. (1994). "The experience of pediatric cancer pain. Part II: Management of pain." *Journal of Pediatric Nursing*, 9(6): 380-387 - Part II of this 2-part qualitative study, includes interviews of 31 family caregivers. Key themes are identified in response to questions about 1) the role of parents in managing their child's cancer pain, 2) how nurses and doctors can help relieve pain, and 3) what advice would these parents give to parents in a similar situation.

Ferrell BR, Rhiner M, Shapiro B, Strause L. (1994). "The family experience of cancer pain management in children." *Cancer Practice*, 11/12(2): 441-446 - This study was conducted in a children's hospital (n=31), and a community hospice (n=8), with family caregivers of pediatric cancer patients as participants. Pain intensity was rated by children with cancer and their caregivers. Quantitative data includes a description of family caregivers knowledge and beliefs about pain.

B. Recommended Books

W Children's Hospice/Home Care: An Implementation Manual for Nurses (Martinson, Martin, Lauer, Birenbaum, & Eng.) order form. To order: Children's Hospice International, 2202 Mt. Vernon Avenue, Suite 3C, Alexandria, VA 22301, (703) 684-0330, (703) 684-0226 Fax, Website: <http://www.chionline.org/>

W Implementation Manual: Establishing Hospice Programs to Serve Children and their Families (Brenner & Zarbock) order form. To order: Children's Hospice International, 2202 Mt. Vernon Avenue, Suite 3C, Alexandria, VA 22301, (703) 684-0330, (703) 684-0226 Fax, Website: <http://www.chionline.org/>

W Home Care for Seriously Ill Children: A Manual for Parents (Martinson & Moldow) order form. To order: Children's Hospice International, 2202 Mt. Vernon Avenue, Suite 3C, Alexandria, VA 22301, (703) 684-0330, (703) 684-0226 Fax, Website: <http://www.chionline.org/>

W Palliative Pain & Symptom Management for Children & Adolescents (Milch, Freeman & Clark) order form. To order: Children's Hospice International, 2202 Mt. Vernon Avenue, Suite 3C, Alexandria, VA 22301, (703) 684-0330, (703) 684-0226 Fax, Website: <http://www.chionline.org/>

W End of Life Care for Children (Texas Children's Cancer Center, Texas Children's Hospital) order form. To order: Children's Hospice International, 2202 Mt. Vernon Avenue, Suite 3C, Alexandria, VA 22301, (703) 684-0330, (703) 684-0226 Fax, Website: <http://www.chionline.org/>

_____ W Chronic and Recurrent Pain in Children and Adolescents: Progress in Pain Research and Management, Vol. 13 order form – Authored by Patrick J. McGrath, PhD & G. Allen Finley, MD, FRCPC provides in-depth reviews of important issues relating to chronic pain in children. Website: <http://www.iasp-pain.org>

_____ W Measurement of Pain in Children by G. Allen Finley & Patrick J. McGrath. ISBN : 0-931092-20-5. IASP Press. Website: <http://www.iasp-pain.org>

C. *Educational Materials/Curriculum*

_____ W Pediatric Patient Education Book - City of Hope, Duarte, California
This booklet, “Your Child’s Comfort: A Team Approach to Managing Your Child’s Cancer Pain” provides parents with information to care for their child’s pain caused by cancer or by procedures used to diagnose and treat the disease.

_____ Pediatric Patient Education Book/Spanish - City of Hope, Duarte, California
(See description above)

_____ Will It Hurt? Pediatric booklet series - U. of California, Los Angeles (1993 version)
- This 3-booklet series provides parents with information to help their infant, child, or teenager while in the hospital, with surgery and pain from other medical procedures.

_____ W Children’s Cancer Pain Can Be Relieved (for parents).
A 12 page booklet in Q&A format. Preview copy free of charge, additional copies \$0.50 plus postage. Distributed by the Wisconsin Cancer Pain Initiative. Download for free, or purchase from Wisconsin Cancer Pain Initiative website <http://www.wisc.edu/wcpi/>

D. *Guidelines/Clinical Pathways*

_____ W Cancer Pain Relief and Palliative Care in Children
World Health Organization (WHO) guidelines on the management of pain in children. Available in English, Spanish, and French. To order: WHO Publication Center, 49 Sheridan Avenue, Albany, NY 12210, (518) 436-9686 X118, E-mail: QCORP@compuserve.com, Website: http://www.who.int/ncd/cancer/publications/books/ca_pain_relief_pall_care_in_children.html

_____ Reference Manual for the Wong-Baker Faces Pain Rating Scale (2000 version) - Donna Wong, PhD, RN, PNP, CPN, FAAN and Connie M. Baker, MS, CLS (\$5.00/copy)
- The Wong-Baker Faces Scale has been used extensively in pediatrics and in other populations. This comprehensive 54-page manual provides information regarding the development, reliability and validity of the tool and suggestions for its use.

_____ W CRIES Tool - Judy Bildner, RNC, MSN, Neonatal Clinical Nurse Specialist; University Hospital & Clinics, Children’s Hospital, Columbia Missouri (1997 version)
Behavioral assessment tool for pain in neonates. Includes self learning module and documentation forms.

W

FLACC Scale (Face, Legs, Activity, Cry, Consolability) -C. S. Mott Children’s Hospital, University of Michigan Medical Center (1996 version)

- Behavior assessment scale for use in non-verbal children or others unable to provide reports of pain . Reliability and validity information provided. For questions regarding this instrument, please contact Sandra Merkel at sandym@med.umich.edu

E. Other Organizations Links

Agency for Healthcare Research and Quality, Child Health	http://www.ahrpr.gov
American Academy of Pediatrics	http://www.aap.org
Association of Pediatric Oncology Nurses (APON)	http://www.apon.org
Candlelighters Childhood Cancer Foundation	http://www.candlelighters.org
Children’s Hospice International	http://www.chionline.org
The Compassionate Friends	http://www.compassionatefriends.org
Make A Wish Foundation	http://www.wish.org
Medical Algorithms Project	http://www.medal.org
National Childhood Cancer Foundation	http://www.nccf.org
National Children’s Cancer Society	http://www.children-cancer.org
National Guideline Clearinghouse	http://www.guideline.gov/body_home.asp
Pediatric Pain	http://is.dal.ca/~pedpain/prohp.html

F. Key References

Neonate packet

W

- Bibliography which includes 22 references – 2002 version
- Pediatric materials resource list – 1997 version

G. Position Statements/Standards

American Pain Society Position Statement on Pediatric Chronic Pain – 2001 version

W

- This position statement is the result of a special committee formed of experts in pediatric pain management. It addresses issues pertinent to pediatric chronic pain such as the definition of chronic pain, assessment, treatment, education issues, research, policy implications, along with references. It is available through the web site of the American Pain Society at <http://www.ampainsoc.org> or by calling 847/375-4715.

ACEP Policy Statement/ Pediatric Analgesia and Sedation - American College of Emergency Physicians

- ACEP Policy Statement on the use of Pediatric Sedation and Analgesia (1992 version)
- Sacchetti A, Schafermeyer R, Gerardi M etc. “Pediatric Analgesia and Sedation.” Annals of Emergency Medicine, 1994; 23-2; 237-250.

American Academy of Pediatrics Position Statement on “The Assessment and Management of Acute Pain in Infants, Children, and Adolescents” (0793) – September, 2001

W

The American Academy of Pediatrics (AAP) and the American Pain Society (APS) jointly issue this statement to underscore the responsibility of pediatricians to take a leadership

and advocacy role to ensure humane and competent treatment of pain and suffering in all infants, children, and adolescents. Website: <http://www.aap.org>

W

American Academy of Pediatrics (AAP) Position Statement on “Prevention and Management of Pain and Stress in the Neonate” (RE9945) – February, 2000

The objectives of this statement are to increase awareness that neonates experience pain; provide a physiological basis for neonatal pain and stress assessment and management by health care professionals; make recommendations for reduced exposure of the neonate to noxious stimuli and to minimize associated adverse outcomes; and recommend effective and safe interventions that relieve pain and stress. Website: <http://www.aap.org/>

W

American Society of Pain Management Nurses (ASPMN) Position Statement on “Neonatal Circumcision Pain Relief” – October, 2001

The ASPMN opposes the participation of nurses and other healthcare professionals in the performance of male neonatal circumcision without an anesthetic to treat the pain inherent in the procedure. Website: <http://www.aspmn.org>

W

American Academy of Pediatrics (AAP) Circumcision Policy Statement (RE9850) – March, 1999

Policy Statement regarding giving a child procedural analgesia (EMLA cream) before performing a circumcision procedure. Website: <http://www.aap.org/>

Costs

Section Description: This section includes several City of Hope publications related to cost issues in pain management.

For more information see VII Family/Home Care, *A. City of Hope Publications*, Item 6.

A. City of Hope Publications

Ferrell BR. (1993). "Cost issues surrounding the treatment of cancer related pain." Journal of Pharmaceutical Care in Pain and Symptom Control, 1(1): 9-23 - This article includes references of cost benefit comparisons of pain modalities used by the health care system in relieving cancer pain. Acquisition, setting, and administration of medication were important components of cost.

Ferrell BR, Griffith H. (1994). "Cost issues related to pain management: Report from the cancer pain panel of the Agency for Health Care Policy and Research." Journal of Pain and Symptom Management, 2(4): 221-234 - Presents a 13-point framework in an attempt to isolate specific cost issues related to pain management. A synopsis of these 13 areas of cost is discussed including the direction of health policy research for the future.

Ferrell BR, Rhiner M. (1994). "Use of technology in the management of cancer pain." Journal of Pharmaceutical Care in Pain and Symptom Control, 2(1): 17-35 - Results of a study of advanced pain technology (APT) for cancer pain management. 136 charts were audited from 9-acute care settings in 3-states. The population consisted of patients who were changed from oral analgesics to a PCA pump. Study findings revealed several areas in which clinical use of pain technology differs from the recommendations made by the World Health Organization and Agency for Health Care Policy and Research.

Grant M, Ferrell BR, Rivera LM, Lee J. (1995). "Unscheduled readmissions for uncontrolled symptoms ." Nursing Clinics of North America, 30(4): 673-682 - This paper summarizes the impact of quality improvement activities in reducing hospital admissions for uncontrolled pain and other symptoms.

Ferrell BR, Schaffner M. (1997). "Pharmacoeconomics and medical outcomes in pain management." Seminars in Anesthesia, 16(2): 152-159 - Overview of cost issues in pain management. Reviews medical and pharmacoeconomic outcomes of pain management.

Jacox A, Carr DB, Mahrenholz DM, Ferrell BM. (August 1997). "Cost considerations in patient-controlled analgesia." Pharmacoeconomics 1997, 12(2 Pt 1): 109-120 - This article reports on studies published between January 1984 and December 1995 which considered cost aspects of PCA.

Ferrell, BR. (2000). "The Cost of Comfort: Economics of Pain Management in Oncology." Oncology Economics, 1(9): 56-61. - This article reviews a framework for evaluating costs associated with pain management. It also discusses important implications for both clinicians and administrators in providing optimum pain relief within the context of the most cost-effective care.

B. Recommended Books

C. Educational Materials/ Curriculum

D. Guidelines/ Clinical Pathways

E. Other Organizations Links

F. Key References

G. Position Statements/ Standards

End of Life/Palliative Care

Section Description: This section includes book order forms, curriculum materials from a home care palliative education project, instruments used in end of life care, course syllabus on End-of-Life Care Content Guidelines, and position statements from professional organizations. Additional information on other resource centers on end-of-life care and information on educational programs such as the End of Life Nursing Education Consortium (ELNEC) is also available. Numerous other resources and information on end-of-life care are presented in the Resource List.

A. City of Hope Publications

Ferrell BR, Virani R, Grant M. (March/April 1998). "HOPE: Home care Outreach for Palliative care Education" Cancer Practice, 6(2): 79-85 - Describes development and implementation of a five component training program for improved end of life care in home care.

Ferrell BR, Virani R, Grant M. (1998). "Improving end-of-life care education in home care." Journal of Palliative Medicine, 1(1): 11-19 - Based on program described above. This article describes five program modules including overview of palliative care, pain management, symptom management, communication and the death event.

_____ Ferrell BR. (1998). "End of life care." Nursing 98, 28(9): 58-60 - Presents a survey of knowledge and beliefs regarding end of life care.

_____ Ferrell BR, Virani R, Grant M. (1999). "Analysis of symptom assessment and management content in nursing textbooks." Journal of Palliative Medicine, 2(2): 161-172 - This paper presents the findings from the textbook review (described in article "5" below) specific to symptom management.

_____ Ferrell BR, Virani R, Grant M. (1999). "Analysis of end-of-life content in nursing textbooks." Oncology Nursing Forum, 26(5): 869-876 - Presents the overall findings of a review of 50 leading nursing texts regarding nine areas of end of life content.

_____ Ferrell BR, Virani R, Grant M. (1999). "Review of communication and family caregiver content in nursing texts." Journal of Hospice and Palliative Nursing, 1(3): 97-107 - Presents the overall findings of a review of 50 leading nursing texts specific to areas of communication and family caregiver content (see article "5" above).

_____ Ferrell BR, Virani R, Grant M, Borneman T. (1999). "Analysis of content regarding death and bereavement in nursing texts." Psycho-Oncology, 8(6): 500-510 - Presents findings from textbook review (see article "5" above) specific to areas of death/bereavement.

_____ Ferrell BR, Grant M, Virani R. (1999). "Strengthening nursing education to improve end-of-life care." Nursing Outlook, 47(6): 252-256 - Describes results of a survey to assess the perceptions of nursing faculty and state boards of nursing on end-of-life care.

_____ Ferrell BR, Virani R, Grant M, Juarez G. (2000). "Analysis of Palliative Care Content in Nursing Textbooks." Journal of Palliative Care, 16(1): 39-47 - This paper reports on the review of end-of-life content in nursing textbooks (see Article "5" above) specific to areas of palliative care defined, quality of life, issues of policy, ethics and law.

_____ Ferrell BR, Virani R, Grant M, Coyne P, Uman G. (2000). "Beyond the Supreme Court Decision: Nursing Perspectives on End-of-Life Care." Oncology Nursing Forum, 27(3): 445-455 - Results of a descriptive cross-sectional survey (N=2,333) describing nurses' views of care of the terminally ill.

_____ Ferrell BR, Virani R, Grant M, Vallerand A, McCaffery M. (2000). "Analysis of Pain Content in Nursing Textbooks." Journal of Pain and Symptom Management, 19(3): 216-228 - This paper presents findings from textbook review (see Article "5" above) specific to areas of pain.

_____ McCahill L, Ferrell BR, Virani R. (2001). "Improving cancer care at the end of life." The Lancet Oncology, 2(February 2001): 103-108 - This paper reviews the critical necessity for reform in end-of-life care for the field of oncology and the major educational efforts required to ensure that oncology professionals can respond to this need.

_____ Ferrell BR (2001). "Caring at the end of life." Reflections, 25(4): 31-45.

Ferrell BR, Borneman T (2002). "Community Implementation of Home Care Palliative Care Education." Cancer Practice, 10(1): 20-27.

Ferrell BR, Coyle N (2002). "An Overview of Palliative Nursing Care." American Journal of Nursing, 102(5): 26-31 – Studies tell us that most people fear a protracted, painful death; unfortunately, this is what many experience. Palliative nursing care seeks to change this. This new series challenges nurses to think differently about caring for people when a cure isn't possible.

Matzo ML, Sherman DW, Mazanec P, Barber, MA, Virani R, McLaughlin MM (2002). "Teaching Cultural Considerations at the End of Life: End of Life Nursing Education Consortium Program Recommendations." Journal of Continuing Education in Nursing, 33(6): 270-278.

B. Recommended Books

W Approaching Death: Improving Care at the End of Life Report of the Institute of Medicine order form. Editors: Marilyn J. Field and Christine K. Cassel. 1997. ISBN # 0-309-06372-8. Order form available at <http://www.nap.edu>

W Dying Well order form. Author: Ira Byock. Published by Riverhead Books, 1998. ISBN # 1573226572. Order form available at <http://www.amazon.com>

W Finding Your Way: A Guide for End-of-Life Medical Decisions order form. Published by Sacramento Healthcare Decisions. Order form available at <http://www.sachealthdecisions.org/>

W Hospice Concepts: A Guide to Palliative Care in Terminal Illness order form. By Shirley Ann Smith, RN, MSN. Order form available at <http://www.researchpress.com>

W Improving Care for the End of Life order form. By Joanne Lynn, M.D., Janice Lynch Schuster, and Andrea Kabcenell, R.N. Oxford University Press, 2000. ISBN # 0195116615. Order form available at <http://www.oup-usa.org> or <http://www.abcd-caring.org>

W Innovations in End-of-Life Care Two Volume Series order form. Edited by Mildred Z. Solomon, Anna L. Romer, Karen S. Heller, and David E. Weissman. Volume 1: ISBN 0-913113-87-5, Volume 2: ISBN 0-913113-92-1. Order form available at <http://www.liebertpub.com/books>

W Palliative Care Nursing Education: Quality Care to the End of Life order form. By Marianne Matzo, PhD, RN, GNP, CS and Deborah Sherman, PhD, RN, ANP, CS. ISBN #: 0-8261-1384-2. Order form available at http://www.springerpub.com/store/page1384_2.html

W Textbook of Palliative Nursing order form. Edited by Betty R. Ferrell and Nessa Coyle. Oxford University Press, 2001. ISBN #0195135741. Order form available at <http://www.oup-usa.org/>

W Text on Suffering order form (1996). Edited by Betty Ferrell with chapters addressing various dimensions of suffering in AIDS, cancer, pediatrics. Order form available at

<http://www.jbpub.com>

W

Principles and Practice of Supportive Oncology order form. By Ann M. Berger, Russell K. Portenoy & David E. Weissman. (Eds.) (2002). Lippincott-Raven: Philadelphia, PA. ISBN #: 0-7817-3324-3. Order form available on Lippincott Williams & Wilkins website at: <http://www.lww.com/productdetailresults/1,2265,507174889,00.html>

W

End of Life Nursing Care by Belinda Poor and Gail P. Poirrier (2001) order form. This 489 page book flows smoothly from historical perspectives to caring for the caregiver; and includes theories, holistic models, the grief process and responses to loss, ethical and legal considerations, patient centered care, communication, management of specific terminal illnesses, and issues across the lifespan. ISBN: 0-7637-1421-6. Jones and Bartlett Publishers. Order form available at <http://nursing.jbpub.com>

W

Hospice and Palliative Care: Concepts and Practice order form. By Denice C. Sheehan and Walter Forman (2003), This 216 page book offers theoretical perspectives and practical information about this growing field. In the first part, the authors present a historical overview of hospice and explain how the interdisciplinary team functions in the hospice setting. In the second part, the authors discuss challenges to the team including symptom management, death education, ethical issues, and support groups. The future of hospice is addressed in the final part. The contributors are experts in community medical care, geriatric care, nursing care, pain management, research, counseling, and hospice management. ISBN #: 0763715662. Jones and Bartlett Publishers. Order form available at <http://nursing.jbpub.com>.

W

Crossing Over: Narratives of Palliative Care. By D. Barnard, AM Towers, P. Boston & L. Yanna. (2000). Oxford University Press. ISBN: 0195123433. Website: <http://www.oup-usa.org>

W

I Don't Know What to Say: How to Help and Support Someone Who is Dying. By R. Buckman (1992). Vintage Books. ASIN: 0679732020. Website: <http://www.amazon.com>

W

Final Gifts: Understanding the Special Awareness, Needs & Communications of the Dying. By M. Callanan & P. Kelley (1992). Bantam Books. ISBN: 0-553-37876-7. Website: <http://www.randomhouse.com>

W

Handbook of Psychiatry in Palliative Medicine. By H.M. Chochinov & W. Breitbart (Eds) (2000). ISBN # 0195092996. Oxford University Press. Website: <http://www.oup-usa.org>

W

Oxford Textbook of Palliative Medicine, Second Edition. By D. Doyle, G. Hanks & N. MacDonald (Eds) (1998). Oxford University Press. ISBN: 0192630571. Website: <http://www.oup-usa.org>

W

The Measure of Our Days. By J. Groopman (1997). Penguin Putnam Inc. ISBN: 014026972X. Website: <http://www.penguinputnam.com>

W Psycho-oncology. By J.C. Holland (Ed) (1998). Oxford University Press. ISBN: 0195106148. Website: <http://www.oup-usa.org>

W Terminal Illness: A Guide to Nursing Care, 2nd edition. By Charles Kemp (1999). J.B. Lippincott Co. ISBN: 0-7817-1772-8. Website: <http://www.lww.com>

W Palliative Medicine: A Case-Based Manual. By N. MacDonald (1998). Oxford University Press, Inc. ISBN: 0192626574. Website: <http://www.oup-usa.org>

C. Educational Materials/Curriculum

W Curriculum materials (\$60.00/copy) – Order Form ONLY Available Online
Home care Outreach for Palliative Care Education (HOPE) training program. The training materials include a 215 page syllabus including participant outlines, detailed faculty teaching outlines, PowerPoint slides, and extensive handout materials.

W Care of the Dying Patient - Video Listing (updated 4/03)
Updated 6 times a year. This project, funded by the Project on Death in America, is a listing of more than 250 videos recommended for use in palliative care education. Compiled by Marianne Matzo, RN, PhD, FAAN.

W Education for Physicians on End-of-Life Care (EPEC)
Ordering information and description of a train the trainer program designed to educate physicians in the essential clinical competencies in end of life care. Program supported by a grant from the Robert Wood Johnson Foundation and sponsored by Northwestern University Medical School. Website: <http://www.epec.net>

W End of Life Care CD-ROM Program – Network for Continuing Medical Education
CD-ROM Program, created by Christine K. Cassel, Diane E. Meier, and R. Sean Morrison, the Mount Sinai team explores the elements of good palliative care and discusses the barriers to adequate pain control for patients in need. Approved for up to 2 credit hours in category 1 (PRA/AMA), 1 prescribed hour (AAFP), AMA category 1 credit accepted (AAPA), and up to 2 credit hours in category 2 (AOA). Website: <http://www.ncme.com/>

End of Life Care Content Guidelines, City of Hope, Duarte, CA (\$5.00/copy) – 1999 version
78 page syllabus including content outlines and references for 9 common end-of-life care topics, i.e. palliative care defined; quality of life at the end of life; pain; symptom management; communication with dying patients and family members; role/needs of family caregivers; dying process and death; ethics, issues of policy and law; bereavement. These outlines are useful to develop curriculum or as content for publications

W End of Life: Exploring Death in America
Presents information on the “End of Life” series from National Public Radio (NPR). Includes an audio file and transcripts from the programs. Highlights issues such as coping with death, palliative medicine, grief and bereavement, funerals, reincarnation, and funeral homes. Includes a list of resources for people with life-threatening diseases and their families. Contains a bibliography of books and journal articles dealing with

terminal illness, bereavement, grief, and medical and social policy relating to the care of the terminally ill. Website: <http://www.npr.org/programs/death/>

W

End of Life Nursing Education Consortium (ELNEC) Project: Advancing End-of-Life Nursing Care

A comprehensive national education program to improve end-of-life care by nurses funded by the Robert Wood Johnson Foundation. Information available on the American Association of Colleges of Nursing (AACN) website: <http://www.aacn.nche.edu/ELNEC>

W

Hospice and Palliative Nursing Practice Review, Third Edition, Hospice and Palliative Nurses Association – 1999 version

A review guide based on current hospice and palliative nursing practice. The updated guide contains materials based on current outcomes revealed by a national job analysis study conducted by the National Board for Certification of Hospice and Palliative Nurses (NBCHPN). ISBN # 0-7872-5680-3. Order form available at <http://www.kendallhunt.com>

W

Instruments Used in End of Life Care Education, City of Hope, Duarte, CA (\$5.00/copy) – 1999 version

- A collection of instruments currently in use by City of Hope investigators to assess staff knowledge and needs to improve end of life care. Curriculum Survey for Nursing Schools; Clinical Nurse Survey; Home Care/Hospice Agencies; Home Care Nurses and HHAs; Knowledge Assessment for Nurses; Knowledge Assessment for HHA's; Chart Audit Tool; Case Analysis Form

W

Tool-Kit for Nursing Excellence at End of Life Transition (TNEEL).

TNEEL is a package of electronic tools for palliative care education (2001). Principal investigator, Diana Wilkie, PhD, RN, AOCN, FAAN, University of Washington, Seattle, WA. View more information about the program on the website:

<http://www.son.washington.edu/departments/bnhs/pain/tneel.asp>

W

Completing a Life: a resource for Taking Charge, Finding Comfort, Reaching Closure

An interactive CD-ROM inviting patients and families to learn about the practical, emotional, spiritual, and medical issues faced by those dealing with advanced illness. The CD-ROM is available now through the [Instructional Media Center](#) at Michigan State University. For CD-ROM ordering information call 517-353-9229 or order directly from the web site: <http://www.completingalife.msu.edu/>

W

Disseminating End-of-Life Education to Cancer Centers (DELEtCC)

A national educational program to prepare interdisciplinary healthcare providers as clinical leaders in end-of-life care for cancer patients and their families. The program is supported by a grant from The National Cancer Institute and sponsored by City of Hope National Medical Center. Website: <http://deletcc.coh.org>

W

Heart-to-Heart: Improving Care for the Dying through Public Policy

This audio program is a must for any policymaker or professional who wants to understand the issues surrounding pain management and what can be done to improve

care of the dying. Distributed by Partnership for Caring. Order on the web at <http://www.partnershipforcaring.org/>, (WHEN ON THE WEBSITE click on “Store Products”, click on “Order Form”, click on Heart-to-Heart under “Audio”).

Graceful Passages

W Interfaith audio resource (CD) to assist caregivers, dying persons, and their families to help transition from denial to acceptance. To order: Companion Arts, P.O. Box 2528, Novato, CA 94948-2528, (415) 209-9408, (888) 242-6608, Website: <http://www.gracefulpassages.com> , E-mail: music@gracefulpassages.com

D. Guidelines/Clinical Pathways

End-Stage Renal Disease Workgroup Report

W Clinicians and researchers working with end-stage renal disease (ESRD) can now access an important palliative care resource online. *Promoting Excellence* announces the availability of “Completing the Continuum of Nephrology Care – the End-Stage Renal Disease Peer Workgroup Recommendations to the Field” at its web site. The report presents the methods, findings, recommendations and products of the ESRD Workgroup sponsored by the *Promoting Excellence in End-of-Life Care* Project. Website: <http://www.promotingexcellence.org/esrd/>

Pioneering Practices in Palliative Nursing Care

W In July 2001, *Promoting Excellence in End-of-Life Care* convened a group of advanced practice nurses (APNs) to hold a conversation on the state of palliative care advanced practice nursing in the United States, to identify gaps in and barriers to that practice and to develop strategies for the future. The report on this important gathering of APNs working in the field of palliative care is now available on the *Promoting Excellence* web site. Website: <http://www.promotingexcellence.org/apn/>

E. Other Organizational Links

American Academy of Hospice and Palliative Medicine <http://www.aahpm.org>
Americans for Better Care of the Dying (ABCD) <http://www.ABCD-caring.org/>
American Board of Hospice and Palliative Medicine <http://www.abhpm.org/>
American Hospice Foundation <http://www.americanhospice.org/>
American Society of Hospice & Palliative Medicine <http://www.aahpm.org/>
American Society of Pain Management Nurses <http://www.aspmn.org>
Association of Death Education and Counseling (ADEC) <http://www.adec.org>
At the End of Life <http://www.aarp.org/contact/programs/endoflife.html>
Before I Die: Medical Care and Personal Choices <http://www.wnet.org/archive/bid/>

Bereavement and Hospice Support Netline	http://www.ubalt.edu/
The Careguide.com	http://www.thecareguide.com/
Center to Advance Palliative Care (CAPC)	http://www.capcmssm.org e-mail: robert.dantuono@mssm.edu
Center for Hospice and Palliative Care	http://www.hospicebuffalo.org/
Center to Improve Care of the Dying	http://www.gwu.edu/~cicd/
Compassion in Dying	http://www.CompassionInDying.org/
Decisions Near the End of Life Education Development Center, Inc.	http://www.edc.org/CAE/Decisions/dnel.html/
Designing an Agenda for the Nursing Profession on End of Life Care, 1999.	http://www.aacn.org/
Dying Well	http://www.dyingwell.org or http://www.dyingwell.com
The Edmonton Palliative Care Program	http://www.palliative.org/
Education for Physicians on End of Life Care (EPEC)	http://www.epec.net/
The End of Life: Exploring Death in America	http://www.npr.org/programs/death/
End of Life Nursing Education Consortium (ELNEC)	http://www.aacn.nche.edu/elnecc/
End of Life Physician Education Resource Center (EPEC)	http://www.eperc.mcw.edu/
European Association for Palliative Care	http://www.eapcnet.org/
Final Thoughts	http://www.finalthoughts.com/
Griefnet	http://www.griefnet.org/
Grief Recovery Online for ALL Bereaved	http://www.groww.org/
Growth House, Inc.	http://www.growthhouse.org/
Harvard Medical School Center for Palliative Care	http://www.hms.harvard.edu/cdi/pallcare/
The Hospice of the Florida Suncoast	http://www.thehospice.org
Hospice and Palliative Nurses Association	http://www.hpna.org/
Hospice Foundation of America	http://www.hospicefoundation.org/
Hospice Hands	http://www.hospicecares.org
Hospice Home Page	http://www.scu.edu/Hospice/
Hospice Net	http://www.hospicenet.org/
Hospice Resources	http://www.hospiceresources.net/
Innovations in End of Life Care	http://www.edc.org/lastacts/
Last Acts Campaign	http://www.lastacts.org/

Missoula Demonstration Project	http://www.missoulademonstration.org/
National Hospice and Palliative Care Organization	http://www.nhpco.org/
National Prison Hospice Association – Development of Hospice Care in Correctional Facilities	http://www.npha.org/
National Public Health: Exploring Death in America	http://www.npr.org/
On Our Own Terms:	http://www.pbs.org/wnet/onourownterms/
Open Society Institute Project on Death in America	http://www.soros.org/death/
Pain Medicine and Palliative Care Resource Center	http://www.stoppain.org/
Palliative Care	http://www.growthhouse.org/
Partnership for Caring: America’s Voices for the Dying	http://www.partnershipforcaring.org/HomePage/
Promoting Excellence in End of Life Care	http://www.promotingexcellence.org/
Sacramento Healthcare Decisions	http://www.sachealthdecisions.org/
Supportive Care of the Dying:	http://www.careofdying.org/
Toolkit of Instruments to Measure EOL Care	http://www.chcr.brown.edu/pcoc/toolkit.htm

F. Key References

W

Palliative Care Services Bibliography
A bibliography compiled by Drs. Andrew Billings and Charles VonGunten regarding organization and development of Palliative Care Services and units.

G. Position Statements/Standards

W

American Nurses Association (ANA) Position Statements:
Promotion of comfort and relief of pain in dying patients;
Assisted Suicide and Euthanasia;
Nursing and the patient self-determination acts;
Nursing care and Do-Not-Resuscitate decisions;
Foregoing nutrition and hydration.
To order and/or to download off the web: American Nurses Association, 600 Maryland Ave, SW, Suite 100 West, Washington, DC 20024, (202) 651-7000, (202) 651-7001 FAX,
Website: <http://www.ana.org>

W

American Society of Pain Management Nurses (ASPMN) Position Statements:
End of Life Care
Assisted Suicide
Website: <http://www.aspmn.org>

W

American Psychological Association Position Statement on End of Life Care
American Psychological Association Fact Sheet on End-of-Life Care. Fact Sheet can be

found on APA website at <http://www.apa.org/pi/eol/factsheet1.pdf>

W

Active Euthanasia and Assisted Suicide, Cancer Pain Management, and ONS and Association of Oncology Social Work Joint Position on End of Life Care
Oncology Nursing Society positions that may be downloaded and printed at no charge from ONS online at <http://www.ons.org> or contact: Oncology Nursing Society, 501 Holiday Drive, Pittsburgh, PA 15220-2749 (412) 921-7373, (412) 921-6565. Website: <http://www.ons.org>

W

Statement on the Scope and Standards of Hospice and Palliative Nursing Practice
This book is a revision of the 1995 Standards of Nursing Practice and Performance. It includes changes in the organizing principles to reflect current practice in both hospice and palliative nursing and to be in agreement with the ANA Standards of Clinical Nursing Practice (1998). ISBN # 0-7872-6766-X. Order from website at <http://www.kendallhunt.com>

NHPCO Task Force Statement on Ethics of Hospice Participation in Research - Casarett D, Ferrell B, Kirschling J, Levetown M, Merriman M, Ramey M, Silverman P
In: Journal of Palliative Medicine [4(4): 441-449] – This task force statement discusses the importance of hospices’ potential contributions to research and describes way in which characteristics of hospice patients, and hospices’ structure, create ethical challenges that may limit these contributions. It concludes by proposing ways in which hospices and national professional organizations can begin to overcome some of these challenges.

W

Advanced Practice Nurses Role In Palliative Care Position Statement – American Nursing Leaders (2002)
Position statement developed through the Advanced Practice Nursing Meeting in Philadelphia in 2001 endorsed by the Promoting Excellence in End-of-Life Care program.

Palliative Surgery

A. City of Hope Publications

Krouse RS, Nelson RA, Ferrell BR, Grube B, Juarez G, Wagman LD, Chu D ZJ. (2001). “Surgical Palliation at a Cancer Center: incidence and outcomes”. Arch Surg, 136(7): 773-778.

McCahill LE, Krouse R, Chu D, Juarez G, Uman G, Ferrell B, Wagman LD (2002). “Indications and Use of Palliative Surgery-Results of Society of Surgical Oncology Survey.” Annals of Surgical Oncology, 9(1): 104-112 – A 110-item survey to test the definition of palliative surgery, assess the extent of use, and evaluate the attitudes and goals of surgeons regarding it was devised for Society of Surgical Oncology members. As a result, palliative surgery is a major portion of surgical oncology practice. Quality-of-life parameters, not patient survival, were identified as the most important goals of palliative surgery.

McCahill LE, Ferrell B (2002). “Palliative surgery for cancer pain.” Western Journal of Medicine, 176: 107-110 – this article discusses surgery as a therapeutic option in the management of pain in cancer patients.

McCahill LE, Krouse RS, Chu D ZJ, Juarez G, Uman G, Ferrell BR, Wagman LD. (2002). "Decision Making in Palliative Surgery." Journal of the American College of Surgeons, 195: 411-423 – surgeons with a cancer-focused practice were surveyed to determine the extent to which palliative surgery was currently practiced, to identify ethical dilemmas and barriers they faced in performing palliative surgery, and to evaluate their treatment choices in four different clinical scenarios.

Cullinane CA, Chu D ZJ, Mamelak AN. (2002). "Current Surgical Options in the Control of Cancer Pain." Cancer Practice, 1 (Suppl 1): S21-S26 – this article reviews the options, indications, and side effects of the interventional and surgical methods available for the treatment of cancer-related pain.

B. Recommended Books

Surgical Oncology Clinics of North America issue titled "The Surgeon and Palliative Care"

(website link only) – January 2001, volume 10, number 1. Website:

<http://www.harcourthealth.com/fcgi-bin/displaypage.pl?isbn=10553207>

C. Educational Materials/Curriculum

D. Guidelines/Clinical Pathways

E. Other Organizational Links

ASCO

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

Society of Surgical Oncology

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

F. Key References

G. Position Statements/Standards

W

Culture

Section Description: This section offers resources related to cultural issues and pain, pocket guides, and guidelines for cultural competency.

A. City of Hope Publications

Juarez G, Ferrell BR, Borneman T. (1998). "Influence of culture on cancer pain management in Hispanic patients (Part I)." Cancer Practice, 6(5): 262-269 - Discussion of the influence of culture on pain management including use of non-drug interventions.

Juarez G, Ferrell BR, Borneman T. (1998). "Perceptions of quality of life in Hispanic patients with cancer (Part II)." Cancer Practice, 6(6): 318-324 - Article focusing on the perceptions of quality of life based on a study of pain management at home with a focus on Hispanic patients.

Juarez G, Ferrell B, Borneman T. (1999). "Cultural considerations in education for cancer pain management." Journal of Cancer Education, 14(3): 168-173 - Article describing a study to evaluate a structure program to educate patients on cancer pain management and compares findings of 3 ethnic groups.

B. Recommended Books

W Culture & Nursing Care: A Pocket Guide order form - UCSF Nursing Press, San Francisco, CA. Editors: Juliene G. Lipson, RN, PhD, FAAN; Suzanne L. Dibble, RN, DNSc; and Pamela A. Minarik, RN, MS, FAAN. This book offers nurses an overview of human diversity, similarities as well as differences between and within various cultural groups. Book order form only.

W Cultural Issues in End-of-Life Decision Making order form - Book intended to prepare nurses, physicians, and other health care workers to provide guidance, insofar as they are most frequently in contact with the patient and his/her family at the time choices must be made. Edited by Kathryn L. Braun, James H. Pietsch, & Patricia L. Blanchette, all at University of Hawaii. Order from Sage Publications at <http://www.sagepub.com>, e-mail: order@sagepub.com

C. Educational Materials/Curriculum

W Fast Facts-5 Minute Inservice
Cultural Aspects of Pain Management

D. Guidelines/Clinical Pathways

W Oncology Nursing Society Multicultural Outcomes: Guidelines for Cultural Competence Document to help nurses to understand the concepts and develop the skills needed to provide culturally competent care. Members may log onto the ONS website at <http://www.ons.org> to download materials. Non-members can go to customer service on the ONS website at <http://www.ons.org>, call 412-921-7373, or e-mail customer.service@ons.org

E. Other Organizational Links

Center for Cross Cultural Health	http://www.crosshealth.com
Cross Cultural Health Care Program	http://www.xculture.org
Cultural Competency and Diversity	http://www.cstprogram.org/
Health Professionals for Diversity	http://www.aamc.org/about/progemph/diverse/
Intercultural Cancer Council	http://www.iccnetwork.org
Intercultural Communication Institute	http://www.intercultural.org
National Cancer Institute's Office of Minority Health Resource Center	http://www.omhrc.gov
Office of Special Population Research	http://ospr.nci.nih.gov/default.htm
Resources for Cross Cultural Health Care	http://www.diversityrx.org

F. Key References

W A bibliography including 36 references to literature regarding cultural issues and pain – 2002 version

W American Society of Law, Medicine & Ethics. Annotated selected bibliography published in 1996 for pain, culture and consent.

G. Position Statements/Standards

Sickle Cell

Section Description: This section includes physician and patient resource guides in pain management in sickle cell as well as clinical pathways for treatment. Videos and guidelines for treatment are also available.

A. City of Hope Publications

B. Recommended Books

_____ **W**
Sickle Cell Pain: Progress in Pain Research and Management order form - Ballis, S.M. (1998). International Association for the Study of Pain, Volume 11. Seattle: IASP Press. To view order form, visit website at: <http://www.painbooks.org/orderfor.html>

_____ **W**
Sickle Cell Disease: Information for School Personnel order form - Sickle Cell Advisory Committee. Trenton, NJ: Special Child, Adult and Intervention Services, New Jersey Department of Health and Senior Services, September 1999. View online at <http://www.state.nj.us/health/fhs/sicklecell/>

C. Educational Materials/Curriculum

_____ **W**
“Sickle Cell Provider Video Course” order form – Georgia Sickle Cell Center, Grady Health System, Atlanta, Georgia. Includes a 10-hr. course designed to educate health care providers about the latest developments in common clinical issues in sickle cell disease treatment.

D. Guidelines/Clinical Pathways

_____ **W**
“Guideline for the Management of Acute and Chronic Pain in Sickle Cell Disease”, 1999 version – American Pain Society publication guideline.

Resource Packet

W

Ordering information for “Sickle Cell Related Pain: Assessment & Management” booklets including proceedings from a New England Conference on Management of Pain in Sickle Cell Disease, a patients guide and a physician quick reference guide.

Sickle Cell Pain Relief Record

Developed by St. Francis Hospital & Medical Center in Hartford, CT. Booklet for pediatric patients record keeping of pain management protocol and visit log.

- Guidelines for Standard of Care of Painful Episodes in Patients with Sickle Cell Disease. Developed by Samir K. Ballas, M.D., FACP, FASCP at Thomas Jefferson University-Jefferson Medical College. Booklet describes assessment and management of sickle cell pain.

- 2 and 7 day version of clinical pathway for sickle cell inpatients with uncomplicated crisis who are admitted for pain control. Developed by University of Pittsburgh Medical Center.

Guideline for the Management of Acute Pain in Sickle Cell Disease, Quick Reference Guide for Emergency Department Clinicians (2001 version). Available from the American Pain Society, 847/375-4715 or e-mail: info@ampainsoc.org. Order form available on the Pain Resource Center website.

W

E. Other Organizational Links

Sickle Cell Disease Association of America, <http://www.sicklecelldisease.org/>
Inc.

The Sickle Cell Information Center – The <http://www.emory.edu/PEDS/SICKLE/>
Georgia Comprehensive Sickle Cell Center at
Grady Health System, Emory University
School of Medicine, Atlanta, GA

F. Key References

G. Position Statements/Standards

HIV/AIDS

Section Description: This section includes books and pamphlet order forms along with information on professional organizations focused on AIDS care.

A. City of Hope Publications

B. Recommended Books

HIV/AIDS: A Guide to Primary Care Management by P.J. Ungvarski & J.H. Flaskerud.
Published by W.B. Saunders Co. ISBN #: 0721673228. Website:

<http://www.us.elsevierhealth.com/>

W

HIV: Nursing and Symptom Management by M.E. Ropka & A.B. Williams. Published
by Jones & Bartlett. ISBN #: 0763705446. Website: <http://www.jbpub.com/>

W

HIV/AIDS Nursing Handbook by Carl Kirton, Dorothy Talotta, Kenneth Zwolski.
Published by Mosby, Inc. ISBN #: 0323003362. Website: <http://www.mosby.com>

W

C. Educational Materials/Curriculum

D. Guidelines/Clinical Pathways

E. Other Organizational Links

AIDS Healthcare Foundation <http://www.aidshealth.org/>

AIDS.org	http://www.aids.org/
American Foundation for AIDS Research (amfAR)	http://www.amfar.org/
APA AIDS Resource Center	http://www.psych.org/aids/
Association of Nurses in AIDS Care (ANAC)	http://www.anacnet.org e-mail: AIDSNUSES@aol.com
Critical Path AIDS Project	http://www.critpath.org/
Elizabeth Glaser Pediatric AIDS Foundation	http://www.pedaids.org/
Gay Men's Health Crisis (GMHC)	http://www.gmhc.org/
HIV/AIDS Treatment Information Service	http://www.hivatis.org/
International AIDS Society	http://www.aidsonline.com/
International Association of Physicians in AIDS Care	http://www.iapac.org/
National AIDS Clearinghouse	http://www.cdcnpin.org
National Association of People with AIDS (NAPWA)	http://www.napwa.org/
National Association on HIV Over Fifty (NAHOF)	http://www.hivoverfifty.org/
National Pediatric HIV/AIDS Center	http://www.pedhivaids.org/
The Body: An AIDS and HIV Information Resource	http://www.thebody.com/index.shtml
The Network Project	http://www.networkproject.org/modules/08/index02.html

F. *Key References*

G. *Position Statements/Standards*

W

Palliative Care for Persons Living with HIV/AIDS including Substance Users
 Position statement from the Association of Nurses in AIDS Care (ANAC), 1999. The position statement can be downloaded on the ANAC website at <http://www.anacnet.org/about/policy.htm>

Research Instruments

Section Description: This section includes numerous clinical and research tools addressing quality of life, pain, psychosocial assessment, medical staff knowledge and attitudes, brief pain surveys, and needs assessments from various sources are included in this section. Knowledge and attitudes surveys address general pain issues and professionals such as nurses, pediatric nurses, rehabilitation professionals, and medical staff. Quality of life tools from the City of Hope are designed for various populations and diseases including patient and family versions and tools adapted for Bone Marrow Transplant, Breast Cancer, and Thyroid conditions.

W

Quality of Life Instruments - City of Hope, Duarte, California
 Patient Version - is a 41-item ordinal scale that measures quality of life through physical, psychological, social, and spiritual domains. This tool has been used extensively in pain and cancer survivorship research. Also includes Spanish version of instrument

Family Version - is a 37-item instrument that measures QOL of a family member caring for a patient with cancer. Also includes Spanish version of instrument
Bone Marrow Transplant Version- is an 84-item tool specific for use in BMT
Breast Cancer Version – is a 46-item tool specific for use in Breast Cancer
Thyroid Cancer Version – is a 34-item tool specific for use in Thyroid Cancer
Ovarian Cancer Version – is a 43-item tool specific for use in Ovarian Cancer

W Nurses' Knowledge and Attitudes Tool - City of Hope, Duarte, California
An instrument to measure knowledge and attitudes regarding pain in health care professionals. Used extensively by clinical settings for several years, this tool provides descriptive data regarding areas of needed pain education. (see Item "14" below for pediatric version).

W Controlling Pain Vignettes - City of Hope, Duarte, California
- The vignettes for use with health care professionals, published in a series in the journal Nursing, provide case vignettes related to patient characteristics (i.e. age, behavior) and pain control. Options are presented along with the "right choice" and its rationale. Useful as a brief survey to assess staff knowledge and decisions regarding pain.

W Pain Audit Tools - City of Hope, Duarte, California
- These tools have been used extensively in pain/QA efforts. Includes pain chart audit instrument, a version for surgical pain, and a patient interview tool. (Also see related articles under V. Quality Improvement, *A. City of Hope Publications*).

W Clinical Decision Making Tool - City of Hope, Duarte, California
This 14-item survey assesses nurses' clinical decision making regarding pain management.

W Family Pain Questionnaire - City of Hope, Duarte, California
- The Family Pain Questionnaire (FPQ) is a sixteen-item ordinal scale that measures the knowledge and experience of a family caregiver in managing chronic cancer pain. This tool can be used in clinical practice as well as research.

W Patient Pain Questionnaire - City of Hope, Duarte, California
- The Patient Pain Questionnaire (PPQ) is a sixteen-item ordinal scale that measures the knowledge and experience of a patient in managing chronic cancer pain. This tool can be useful in clinical practice as well as for research.

W Psychosocial Pain Assessment Form - City of Hope, Duarte, California (1995 version)
- Developed by Supportive Care Services, this 7-page assessment/interview form measures the impact of pain on five areas; economics, social support, activities of daily living, emotional problems, and coping behaviors as perceived by the interviewer, patient and significant other.

W Multidimensional Affect and Pain Scale (MAPS) - College of Physicians & Surgeons, New York, NY (1995 version)

- Developed at the College of Physicians and Surgeons of Columbia University, this 30 page packet provides a combined affect and pain questionnaire. There is also a 21 page update included.

W Medical Staff Knowledge & Attitudes Pain Survey - Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire (1995 version)

- 46 item instrument used to assess medical staff regarding knowledge and attitudes regarding pain.

W Brief Pain Surveys (1996 version)

- This is a collection of 6 brief surveys: Pain Assessment/Behavior Survey; Pain/Gender Survey; Brief Cancer Pain Information Survey; Pain Addiction Survey; Brief Pharmacology Survey; Test Questions. These short surveys developed by Margo McCaffery and Betty Ferrell are intended for practical use in situations such as staff education where limited time and resources are available for data collection or analysis.

W RN Needs Assessment: Pain Management - U. of Wisconsin Hospitals & Clinics, Madison, WI (1996 version)

This two-page survey assists in planning continuing education programs in pain management for nurses.

W Rehabilitation Professionals' Knowledge and Attitudes Survey Regarding Pain – Boston School of Occupational Therapy, Boston, Massachusetts

This instrument was developed as an inter-disciplinary tool to assess knowledge and attitudes regarding pain in rehabilitation professionals. This tool was developed using the OT/PT IASP Pain Curriculum in conjunction with 6 clinical experts.

W Pediatric Nurses' Knowledge and Attitudes Survey Regarding Pain – Children's Medical Center of Dallas, Texas (1999 version).

Instrument to assess pediatric nurses' knowledge and attitudes regarding pain in children. Answer key also provided. (also see item 16 below for tool kit project)

W Toolkit of Instruments to Measure End of Life Care (TIME).

This is an extensive website, funded by the Robert Wood Johnson Foundation, and developed and maintained by Joan Teno, MD, MS at Brown University. It includes an Executive Summary reporting the status and need of instruments in end of life care along with listings, links, and access to various instruments measuring various aspects of EOL care. Slide presentations are also available at the site and drafts of previous instruments can be found at the site. Instrument sections are divided as follows: Quality of Life, Pain and other symptoms, Emotional and cognitive symptoms, survival time and aggressive of care, advance care planning, continuity of care, spirituality, grief and bereavement, caregiver well-being, and patient centered reports (e.g. satisfaction) with quality of care. <http://www.chcr.brown.edu/pcoc/toolkit.htm>

W Edmonton Assessment Tools

Online tools to measure discomfort and symptom assessment of dying patients. Tools provided by: Edmonton Palliative Care Program, University of Alberta, Edmonton, Alberta, Canada, Website: <http://www.palliative.org>

W The Quality of Life Instruments Database (<http://195.101.204.50:8081>) Contains a list of over 1000 Patients' Reported Outcomes (PRO) Instruments, detailed descriptive information on over 300 instruments, the copy of 170 original questionnaires and 100 translations, over 50 user manuals. It was developed by the Information Resources Centre of Mapi Research Institute in collaboration with Dr. Marcello Tamburini, Director, Unit of Psychology, National Cancer Institute, Milan, Italy. It is structured in two levels of access. The first level is accessible to all users free of charge and contains for over 300 instruments the full and abbreviated name of the questionnaire, author(s), objective, pathology, disease, type of instrument, population, mode of administration, original language and list of translations. The second level based on yearly subscriptions provides all of the above information plus a copy of the original questionnaire, translations when available, bibliographic references and related websites. Website: <http://195.101.204.50:8081>

W Brief Pain Inventory (BPI)
The BPI (1994) is a brief, simple, and easy to use tool for the assessment of pain in both clinical and research settings. The BPI uses simple numeric rating scales from 0 to 10 that are easy to understand and easy to translate into other languages. It is a well-validated instrument to measure pain intensity, functionality and the impact of pain on one's life in the past 24 hours and within the past week. It was developed by Charles Cleeland, PhD and is available through the Pain Research Group at MD Anderson Cancer Center. A long version and short version are available. For permission to use in clinical or research settings, contact Tito Mendoza, PhD, Pain Research Group, M.D. Anderson Cancer Center, 1100 Holcombe Blvd., Box 221, Houston, TX 77030; e-mail: tmendoza@mdanderson.org; Fax: 713-745-3475. Website: <http://www.mdanderson.org>

W M.D. Anderson Cancer Center Symptom Inventory (MDASI)
The MDASI is used for patients with symptoms due to cancer and cancer treatment to assess the severity of multiple symptoms and the impact of symptoms on daily functioning. To view the MDASI, visit website at <http://www.mdanderson.org/departments/prg/dIndex.cfm?pn=0EE78204-6646-11D5-812400508B603A14>

W McGill Pain Questionnaire
The McGill Quality of Life Instrument (Cohen, 1995) is a 20-item scale specifically developed to measure quality of life at the end of life. A revised version of this instrument (Cohen SR., Mount BM, Bruera E., et al. 1997) has been developed. The MQOL was designed to measure quality of life of people at all stages of a life-threatening illness. The MQOL assesses general domains applicable to all patients, incorporates the existential domain, balances physical and non-physical aspects of quality of life, and includes both positive and negative influences on quality of life.

McGill Short-Form Pain Questionnaire

W The McGill Short Form Pain Questionnaire is a patient-reported instrument that employs 16 items plus a single-item global scale, each with a 2-day time frame. There are five domains that include: physical well-being, physical symptoms, psychological, existential, and support. The instrument was designed to be general in nature in order to maintain brevity and to assure applicability to all patients. It has been used in various terminally ill patients.

Memorial Symptom Assessment Scale

W The MSAS (Portenoy, 1994) is a 32-item verbal rating scale that measures psychological and physical symptoms with regard to their presence, frequency, severity, and degree of distress associated with them. The MSAS has been shown to be reliable and valid. Additionally, the MSAS assesses both physical and emotional symptoms. A copy of the instrument is available at <http://www.chcr.brown.edu/pcoc/msas.pdf>.

FACT-G and FACIT Family of Instruments

W Functional Assessment of Cancer Therapy, version 4, is a 27-item scale developed to measure health-related quality of life in patients undergoing cancer treatment. THE FACT measures four domains of quality of life (physical well-being, functional well-being, social/family well-being, emotional well-being). The measurement system began as a cancer-specific but has expanded to include other chronic illnesses as well. The FACIT family of instruments assesses the health-related quality of life of people living with chronic illnesses. The FACIT measurement system includes the FACT core questionnaire and supplemental sub-scales and the Functional Assessment of Human Immunodeficiency Virus Infection, the Functional Assessment of Multiple Sclerosis (FAMS) and an instrument for use with patients with Parkinson's Disease. The FACT and FACIT Family of Instruments is available at <http://www.facit.org> or through The Center on Outcomes, Research, and Education at Evanston Northwestern Hospital, 1001 University Place, Suite 100, Evanston, IL 60201, phone: 847-570-7370 or fax: 847-570-8033, e-mail: d-cella@northwestern.edu

MOS 36-item short-form health survey

W A short-form tool constructed to survey health status in the Medical Outcomes Study. The SF-36 was designed for use in clinical practice and research, health policy evaluations, and general population surveys. The SF-36 includes one multi-item scale that assesses eight health concepts. It has been used extensively in QOL research in studying adjustment to various chronic illnesses and it has been translated into over 40 languages. The SF-36 and shortened versions of the tool are available through Quality Metric Inc at <http://www.qmetric.com> or at <http://www.sf36.com>

Instruments Used in End of Life Care Education, City of Hope, Duarte, CA (\$5.00/copy) – 1999 version

- A collection of instruments currently in use by City of Hope investigators to assess staff knowledge and needs to improve end of life care. Curriculum Survey for Nursing Schools; Clinical Nurse Survey; Home Care/Hospice Agencies; Home Care Nurses and HHAs; Knowledge Assessment for Nurses; Knowledge Assessment for HHA's; Chart Audit Tool; Case Analysis Form

Promoting Excellence in End of Life Care

W This website includes validated tools for clinical assessment and research in Palliative Care. A copy of the instrument is available at <http://www.promotingexcellence.org>, click on "Instruments", "Clinical Assessment and Research Tools", and then view the list of tools posted by clicking on "Tools Listed by Topic."

Legal/Regulatory Issues

Section Description: This section includes annotated bibliographies and resources pertinent to legal and regulatory issues related to pain management.

A. City of Hope Publications

B. Recommended Books

C. Educational Materials/Curriculum

D. Guidelines/Clinical Pathways

W

Model Guidelines for the Use of Controlled Substances for the Treatment of Pain. Produced by the Federation of State Medical Boards of the United States, Inc. View guidelines on website at : <http://www.fsmb.org/>

W

Achieving Balance in National Opioids Control Policy: Guidelines for Assessment. Produced by the World Health Organization, 2000. This 37 page document provides 16 guidelines that can be used by governments and health professionals to assess the national opioids control policies and their administration of any country to determine if they contain the provisions, procedures and cooperation that are necessary to ensure the availability of opioid analgesics. View the guidelines on the WHO website at: <http://www.medsch.wisc.edu/painpolicy/publicat/00whoabi/00whoabi.htm>

E. Other Organizations Links

American Society of Law, Medicine & Ethics

<http://www.aslme.org>

Pain and the Law

<http://www.painandthelaw.org>

Pain & Policy Studies Group –
University of Wisconsin

<http://www.medsch.wisc.edu/painpolicy>

Comprehensive Cancer Center

F. Key References

W

American Society of Law, Medicine & Ethics. Annotated selected bibliography for Licensure and Discipline as it relates to pain management. Includes general articles, substance abuse issues and court cases (1997 version).

G. Position Statements/Standards

W

A joint statement from 21 health organizations and the Drug Enforcement Administration on “Promoting Pain Relief and Preventing Abuse of Pain Medications: A Critical Balancing Act” – the roles of both health professionals and law enforcement personnel in maintaining the balances between patient care and diversion prevention are critical. To view online, visit the website at <http://www.aspmn.org/html/JSpainrelief.htm>

Pain Assessment Tools

Section Description: This section includes various tools to assess pain and its management. Specifically, pocket reference cards, rating scales, assessment packets, chart forms, database tools, home health flow sheets, chart documentation packets, and tools for infant and pediatric pain assessment are among the resources available.

Pain Assessment Pocket Cards Packet

This is a collection of pain assessment scales created for easy access by professionals or patients.

- Patient Version - City of Hope, Duarte, California
- Professional Version - City of Hope, Duarte, California

W Pain Assessment Guide - University Hospital – Colorado. The Pain Assessment Guide has also been translated into Russian, Vietnamese, Croatian, French, and Arabic by staff at Bryan LGH Medical Center in Lincoln, Nebraska (1999 version). Order form provided to order the translated versions (1999 version).

Pain Rating Instrument order form - Johns Hopkins University, Baltimore, MD

W Order form to obtain instrument developed by Johns Hopkins Oncology Center, the Hopkins Pain Rating Instrument (HPRI) a self-contained, portable 5x20 cm plastic visual analogue scale (VAS) with a sliding marker (1999 version).

Multi-lingual Pain Scales - St. Vincent's Hospital & Med. Ctr., New York, NY (1998 version)

- Developed by Nursing Department of St. Vincent's Hospital and Med Ctr. This 12 page packet includes pain scales written in 11 different languages (Chinese, French, German, Greek, Hebrew, Italian, Japanese, Pakistan, Polish, Russian, Spanish).

Pain Assessment Packet/Chart Forms - Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire

W

W QI Data Collection Tool (1995 version)

Brief patient interview and chart audit tool.

W Post-operative Pain Management Needs Assessment (1995 version)

Tool as well as needs assessment for surgical pain.

W Initial Pain Rating Tool & Pain Flow Sheet (1995 version)

Initial pain assessment and pain flow sheet

Pain Assessment Packet/Chart Forms - Via Christi Regional Medical Center-St. Francis Campus, Wichita, KS

W

Initial Pain Assessment for Pediatric Use (1996 version)

Initial Pain Assessment for Adult Use (1996 version)

Pain Flow Sheet for adults and pediatrics (1996 version)

One-page documentation form used to record pain assessment along with pharmacologic or non pharmacologic interventions.

Pain Assessment Packet/Chart Forms

W Initial Pain Assessment Tool - Margo McCaffery, RN, MS, FAAN and Alexandra Beebe, RN, MS, OCN (1996 version)

A charting form to be used on the patient's initial hospital admission to document location, intensity, quality of pain, and relief.

W Nursing Assessment and Care Plan - City of Hope, Duarte, CA (1995 version)
Comprehensive pain assessment tool for use in initial evaluation of patients referred to a pain service.

W Pain Rating Scales - Wisconsin Cancer Pain Initiative (1996 version)
The three pain rating scales included are: 0-10 visual analog scale, Wong-Baker Faces rating scale and the verbal scale.

- Interdisciplinary Pain Flowsheet - Vancouver Hospital & Health Sciences Centre, Vancouver, BC (1997 version) - chart includes faces scale and visual analog scale

W Pain Assessment Tool Packet - U. of Massachusetts, Worcester, MA
Follow Up Visit Tool (1996 version)
Ambulatory Services Database Tool (1996 version)
Initial assessment tool and follow up clinic assessment for patients with acute, chronic or cancer pain.

W Home Health Pain Management Flow Sheet - U. of Wisconsin Hospitals & Clinics, Madison, WI (1996 version)
- A one-page pain management flow sheet to be used in the home care setting.

Chart Documentation Packet - Department of the Army, Tripler Army Medical Center, Tripler, Hawaii
- PACU Care Plan, PACU Care and Monitoring Flowsheet (1997 version)
- Nursing History and Assessment (1997 version)
- Pain Assessment Flow Sheet (1997 version)

Related Organizations and Websites

Section Description: This section includes various professional and patient organizations focused on pain management or end-of-life care. Website links are provided.

A

Agency for Healthcare Research and Quality – <http://www.ahrq.gov/>

Aging with Dignity – <http://www.agingwithdignity.org>

Alzheimer's Association – <http://www.alz.org>

American Academy of Hospice and Palliative Medicine (AAHPM) – <http://www.aahpm.org>

American Academy of Pain Medicine (AAPM) – <http://www.painmed.org>

American Academy of Pediatrics (AAP) – <http://www.painmed.org>

American Alliance of Cancer Pain Initiatives (AACPI) – <http://www.aacpi.org>

American Association of Critical Care Nurses – <http://www.aacn.org/>

American Association of Pastoral Counselors – <http://www.aapc.org/>

American Association for Therapeutic Humor – <http://www.aath.org/>

American Board of Hospice and Palliative Medicine – <http://www.abhpm.org>

American Board of Internal Medicine – Care for the Dying, Physician Narratives – <http://www.abim.org/pubs/narr001.htm>

American Cancer Society (ACS) – <http://www.cancer.org>

American Chronic Cancer Pain Association – <http://www.theacp.org>

American Chronic Pain Association (ACPA) – <http://www.theacpa.org>

American College of Rheumatology – <http://www.rheumatology.org/>

American Council for Headache Education – <http://www.achenet.org>
 American Geriatrics Society – <http://www.americangeriatrics.org/>
 American Headache Society – <http://www.ahsnet.org/>
 American Health Decisions – <http://www.ahd.org/>
 American Holistic Nurses Association – <http://www.ahna.org>
 American Hospice Foundation – <http://www.americanhospice.org>
 American Hospital Association – <http://www.aha.org>
 American Massage Therapy Association – <http://www.amtamassage.org>
 American Medical Association – <http://www.ama-assn.org.80/about.htm>
 American Music Therapy Association – <http://www.namt.com>
 American Nurses Association – <http://www.ana.org>
 American Nurses Association Code of Ethics – <http://www.ana.org/ethics>
 American Pain Foundation – <http://www.painfoundation.org>
 American Pain Society (APS) – <http://www.ampainsoc.org>
 American Society for Action on Pain – <http://www.asappain.com>
 American Society for the Advancement of Palliative Care – <http://www.asap-care.com>
 American Society for Bioethics and Humanities – <http://www.asbh.org>
 American Society of Anesthesiologists – <http://www.asahq.org>
 American Society of Clinical Oncology – <http://www.asco.org>
 American Society of Hospice & Palliative Medicine – <http://www.aahpm.org>
 American Society of Law, Medicine & Ethics – <http://www.aslme.org>
 American Society of Pain Management Nurses (ASPMN) – <http://www.aspmn.org>
 American Society of Psychosocial and Behavioral Oncology/AIDS – <http://www.ipos-aspboa.org>
 American Society of Regional Anesthesia and Pain Medicine – <http://www.asra.com>
 Americans for Better Care of the Dying (ABCD) – <http://www.abcd-caring.org>
 Approaching Death: Improving Care at the End of Life –
<http://www.nap.edu/readingroom/books/approaching>
 Arthritis Foundation – <http://www.arthritis.org>
 Association for the Care of Children’s Health (ACCH) – <http://www.acch.org>
 Association of American Sickle Cell Disease – <http://www.sicklecelldisease.org>
 Association of Cancer Online Resources, Inc. – <http://www.medinfo.org> or <http://www.acor.org>
 Association of Clinical Pastoral Education – <http://www.acpe.edu>
 Association of Death Education and Counseling (ADEC) – <http://www.adec.org>
 Association of Nurses in AIDS Care (ANAC) – <http://www.anacnet.org>
 Association of Oncology Social Work (AOSW) – <http://www.aosw.org>
 Association of Pediatric Oncology Nurses (APON) – <http://www.apon.org>

B

Before I Die: Medical Care and Personal Choices – <http://www.wnet.org/archive/bid>
 Bereavement and Hospice Support Netline – <http://www.ubalt.edu/www/bereavement>
 Beth Israel Medical Center: MAYDAY Resource Center for Pain Medicine and Palliative Care –
<http://www.stoppain.org>

C

CARF - The Rehabilitation Accreditation Commission – <http://www.carf.org/>
 Cancer.gov – <http://www.cancer.gov>
 Cancer Books for Children – <http://mel.lib.mi.us/health/cancerbooks/>
 Cancer Care, Inc. – <http://www.cancercare.org>
 CancerFatigue.org – <http://www.cancerfatigue.org/>
 Cancer Hope Network – <http://www.cancerhopenetwork.org>

Cancer Kids – <http://www.cancerkids.org>
Cancer Library – <http://www.medhip.usa.net/cancer.html>
Cancer Links – <http://charm.net/~kkdk>
Cancer Net – <http://cancernet.nci.nih.gov/>
Cancer-Pain.org – <http://www.cancer-pain.org/>
Cancer Pain Management in Children – <http://www.childcancerpain.org/>
Cancer Pain Release – <http://www.whocancerpain.wisc.edu/>
Candlelighters Childhood Cancer Foundation – <http://www.candlelighters.org>
Care of the Dying Patient – <http://manestra.tec.nh.us/deathcare>
Caregiver Network – <http://www.caregiver.on.ca/index.html>
Caregiver Survival Resources – <http://www.caregiver911.com>
Catholic Health Association of the United States – <http://www.chausa.org>
Center for Bioethics/Clinical Research Institute of Montreal – <http://www.Ircm.qc.ca/bioethique/english>
Center to Improve Care of the Dying – <http://www.gwu.edu/~cicd>
Center for Medical Ethics and Mediation – <http://www.cmem.org/>
Center to Advance Palliative Care (CAPC) – <http://www.capcmssm.org>
Center to Improve Care of the Dying – <http://www.gwu.edu/~cicd>
Children’s Hospice International – <http://www.chionline.org>
Children’s Organ Transplant Association – <http://www.cota.org>
Choice in Dying – <http://www.partnershipforcaring.org>
Community-State Partnerships to Improve End-of-Life Care – <http://www.midbio.org>
Compassion in Dying Federation – <http://www.compassionindying.org>
The Compassionate Friends, Inc. (TCF) – <http://www.compassionatefriends.org>
Complementary/Integrative Medicine – <http://www.mdanderson.org/departments/cimer/>
Corporate Angel Network, Inc. (CAN) – <http://www.corpangelnetwork.org>
Crisis Grief and Healing – <http://www.webhealing.com>
Cross Cultural Health Care Program – <http://xculture.org>
Cynergy Group (equianalgesic calculator) – <http://www.cynergygroup.com>

D

Decisions Near the End of Life at Education Development Center, Inc. – <http://www.edc.org/CAE/Decisions/dnel.html>
Department of Health and Human Services, Healthfinder – <http://www.healthfinder.gov>
Dying Well – <http://www.dyingwell.org> or <http://www.dyingwell.com>

E

The Edmonton Palliative Care Program – <http://www.palliative.org>
Education for Physicians on End-of-Life Care – <http://www.epec.net/>
Elizabeth Kubler Ross, M.D., “On Death and Dying” – <http://www.elisabethkublerross.com/>
End of Life Care for Children (funded by the Texas Cancer Council) – <http://www.childendoflifecare.org>
The End of Life: Exploring Death in America – <http://www.npr.org/programs/death/>
End of Life Nursing Education Consortium – <http://www.aacn.nche.edu/elnec>
End of Life Physician Education Resource Center (EPERC) – <http://www.eperc.mcw.edu/>
European Association of Palliative Care – <http://www.eapcnet.org/>

F

FACCT – The Foundation for Accountability – <http://www.facct.org/>
Family Caregiver Alliance – <http://www.caregiver.org>
Fibromyalgia Network – <http://www.fmnetnews.com>

G

Griefnet – <http://www.griefnet.org>

Grief Recovery Online for ALL Bereaved – <http://www.groww.org>
Growth House – <http://www.growthhouse.org>
Guide to Internet Resources for Cancer – <http://www.cancerindex.org>
Gunderson Lutheran Program for Improving End-of-Life Care – <http://www.gundluth.org/eolprograms/>
H
Harvard Medical School Center for Palliative Care – <http://www.hms.harvard.edu/cdi/pallcare>
Hospice Association of America – <http://www.hospice-america.org/>
Hospice and Palliative Nurses Association (HPNA) – <http://www.hpna.org/>
The Hospice of the Florida Suncoast – <http://www.thehospice.org>
Hospice Foundation of America – <http://www.hospicefoundation.org>
Hospice Hands – <http://www.hospice-cares.com>
Hospice Resources – <http://www.hospiceresources.net>
I
Innovations in End of Life Care – <http://www.edc.org/lastacts/>
Institute for Healthcare Improvement – <http://www.ihl.org>
Intercultural Cancer Council – <http://icc.bcm.tmc.edu> or <http://iccnetwork.org/>
International Association for the Study of Pain (IASP) – <http://www.iasp-pain.org>
International Association of Hospice Studies –
<http://som.flinders.edu.au/FUSA/PalliativeCare/links/links.htm>
J
Joint Commission Accreditation of Healthcare Organizations – <http://www.jcaho.org>
K
KidsHome at NCI – <http://icicc.nci.nih.gov/occdocs/KidsHome.html>
L
Last Acts – <http://www.lastacts.org>
Leukemia Society of America – <http://www.leukemia.org>
M
Make A Wish Foundation – <http://www.wish.org>
Management of Cancer Pain – <http://www.ahcpr.gov/consumer/>
The Mayday Pain Project – <http://www.painandhealth.org>
Medical College of Wisconsin Palliative Care Programs – <http://www.mcw.edu/bioethics/>
Memorial Sloan Kettering Cancer Center – <http://www.mskcc.org>
Michigan Electronic Library: Health Information Resources – <http://mel.org/health/health-disease-cancer-ch.html>
Midwest Bioethics Center – <http://www.midbio.org>
Missoula Demonstration Project – <http://www.missoulademonstration.org>
N
Nathan Cummings Foundation – <http://www.ncf.org/>
National AIDS Clearinghouse – <http://www.cdcnpin.org/hiv/start.htm>
National Association for Home Care (NAHC) – <http://www.nahc.org/>
National Cancer Institute (NCI) – <http://www.nci.nih.gov>
The National Center for Advanced Illness Coordinated Care – <http://www.coordinatedcare.net/>
National Center for Complementary and Alternative Therapies – <http://nccam.nih.gov>
National Center for Health Statistics – <http://www.cdc.gov/nchs/>
National Childhood Cancer Foundation – <http://www.nccf.org>
National Children’s Cancer Society – <http://www.children-cancer.org>
National Chronic Pain Outreach Association (NCPOA) –
<http://neurosurgery.mgh.harvard.edu/ncpainoa.htm>
National Coalition for Cancer Survivorship (NCCS) – <http://www.cansurvivorship.org>

National Family Caregivers Association – <http://www.nfcacares.org/>
National Headache Foundation – <http://www.headaches.org>
National Health Council – <http://www.nhcouncil.org>
National Hospice and Palliative Care Organization (NHPCO) – <http://www.nhpc.org>
The National Institute of Aging – <http://www.nih.gov/nia/>
National Institute on Aging Alzheimer’s Disease Education and Referral Center –
<http://www.alzheimers.org>
National Organization for Rare Disorders – <http://www.rarediseases.org>
National Patient Air Travel Helpline (NPATH) – <http://www.npath.org>
National Prison Hospice Association – <http://www.npha.org>
National Public Health: Exploring Death in America – <http://www.npr.org>
National Vulvodynia Association – <http://www.nva.org>
Neuropathy Association – <http://www.neuropathy.org>
New York State Partnership for Long-Term Care – <http://www.nyspltc.org/about/index.html#3>
Not Dead Yet – <http://acils.com/NotDeadYet/>
O
On Our Own Terms: Moyers on Dying in America – <http://www.pbs.org/wnet/onourown/terms>
OncoLink – <http://www.oncolink.com/>
Oncology Nursing Society – <http://www.ons.org>
Oncology Pain Page – <http://oncolink.upenn.edu/specialty/pain>
Online Pain Journals – <http://www.pain.com/onlinepainjournal/default.cfm>
Open Society Institute Project on Death in America – <http://www.soros.org/death.html>
Oregon Fibromyalgia Foundation – <http://www.myalgia.com>
Oregon Health Sciences University Center for Ethics in Health Care –
<http://www.ohsu.edu/ethics/>
P
Pain.com – <http://www.pain.com>
Pain Link – <http://www.edc.org/PainLink>
Pain Management and Chemical Dependency – <http://www.painandchemicaldependency.org/>
Pain Medicine and Palliative Care Resource Center –
http://www.stoppain.org/education_research/index.html
Pain Net – <http://www.painnet.com>
Pain Solution Associates – <http://www.painsolutionassociates.com>
Palliative Care: One Vision, One Voice (Palliative Care Nursing) –
<http://www.palliativecarenursing.net>
The Palliative Medicine Program – <http://www.mcw.edu/pallmed>
Partners Against Pain – <http://www.partnersagainstpain.com>
Partnership for Caring, Inc. – <http://www.partnershipforcaring.org>
The Patient Education Institute – <http://www.patient-education.com>
Pediatric Pain – <http://is.dal.ca/~pedpain/prohp.html>
Postoperative Pain Project – <http://www.wisc.edu/trc/projects/pop/>
Project on Death in America (PDIA) – <http://www.soros.org/death.html>
Promoting Excellence in End of Life Care – <http://www.promotingexcellence.org>
R
RAND/IHI Initiative to Improve Quality at the End of Life – <http://www.medicaring.org/>
Reflex Sympathetic Dystrophy Association of America – <http://www.rsds.org/>
Reflex Sympathetic Dystrophy Association of California – <http://www.rsdsa-ca.org>
The Resource Center of the American Alliance of Cancer Pain Initiatives – <http://www.aacpi.org>

Robert Wood Johnson Foundation (RWJF) – <http://www.rwjf.org>

S

Sacramento Healthcare Decisions – <http://www.sachealthdecisions.org>

Shaare Zedek Cancer Pain & Palliative Care Reference Database (Nathan I. Cherny) –
<http://cherny.roxane.com>

Sickle Cell Disease Association of America, Inc. – <http://www.sicklecelldisease.org>

Sickle Cell Information Center – <http://www.emory.edu/PEDS/SICKLE/index.htm>

Southern California Cancer Pain Initiative (SCCPI) – <http://sccpi.coh.org>

StopPain.org – <http://www.stoppain.org/>

Supportive Care of the Dying – <http://www.careofdying.org>

T

TMJ Association, Ltd. – <http://www.tmj.org>

Talarian Map-Cancer Pain – <http://www.talaria.org/>

Telemedicine Information Exchange – <http://tie.telemed.org>

Toolkit of Instruments to Measure End of Life Care –

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

U

United Hospital Fund of New York – <http://www.uhfnyc.org>

University of Wisconsin Pain & Policy Studies Group – <http://www.medsch.wisc.edu/painpolicy>

V

VZV Research Foundation, Inc. – <http://www.vzvfoundation.org>

The Vulvar Pain Foundation – <http://www.vulvarpainfoundation.org>

W

WebMD – Fibromyalgia Message Board with Kim Jones, RN, PhD, FNP – <http://www.webmd.com>

The Wellness Community – Phone: (888) 793-WELL

Worldwide Congress on Pain – <http://www.pain.com>

Other Resources

A. Audio Resources

Academy for Guided Imagery

Academy for Guided Imagery, P.O. Box 2070, Mill Valley, CA 94942, (800) 726-2070.

Website: <http://www.interactiveimagery.com/>

American Pain Society (APS)

American Pain Society, 4700 W. Lake Avenue, Glenview, IL 60025, (847) 375-4715,

Website: <http://www.ampainsoc.org/>

Coping Skills for Bone Marrow Transplantation

Behavioral Sciences, Fred Hutchinson Cancer Research Center, 1100 Fairview Avenue
N., FM815, Seattle, WA 98109-1024, (206) 667-5022, FAX: (206) 667-6356

Exceptional Cancer Patients

Touch Star Productions, 522 Jackson Park Drive, Medville, PA 16335, (800) 759-1294

or (814) 337-8192, FAX: (814) 337-0699, Website: <http://www.touchstarpro.com>, e-

mail: kcb@touchstarpro.com

International Association for the Study of Pain (IASP)

IASP Secretariat, 909 NE 43rd Street, Suite 306, Seattle, WA 98105, (206) 547-6409.

(206) 547-1703 FAX, Website: <http://www.iasp-pain.org>, e-mail: mail to:

IASP@locke.hs.washington.edu

National Hospice and Palliative Care Organization (NHPCO)
National Hospice and Palliative Care Organization, 1901 North Moore Street, Suite
901, Arlington, VA 22209, (703) 243-5900, (703) 525-5762 FAX, Website:
<http://www.nhpc.org/>

Oncology Nursing Society (ONS)
Oncology Nursing Society, 501 Holiday Drive, Pittsburgh, PA 15220-2749, (412) 921-
7373, (412) 921-6565 FAX, Website: <http://www.ons.org/>

Partnership for Caring
Partnership for Caring, Attention: Heart-to-Heart, P.O. Box 1854, Merrifield, VA
22116-9617, 1-800-989-9455, E-mail: pfc@partnershipforcaring.org

B. Video Listing

(please refer to “Care of the Dying Patient” video listing in **XI. End of Life/Palliative Care**, *C. Educational Materials/Curriculum*, Page 91).

C. Journals/Newsletters

ABCD Exchange – a newsletter from Americans for Better Care of the Dying (ABCD). ABCD aims to enhance the experience of the last phase of life for all Americans, advocate for the interests of patients and their families, improve communication between providers and patients, involve society in end-of-life care, and demand continuity in services for the seriously ill. Website: <http://www.abcd-caring.org>, E-mail: caring@erols.com

THE ACPA Chronicle – a patient-oriented quarterly newsletter of the American Chronic Pain Association. It includes letters, essays, articles, and book reviews written by people with chronic pain or their families. Periodically, healthcare professionals have inclusions. Website: <http://www.theacpa.org>

American Journal of Hospice & Palliative Care – A peer reviewed research journal published bi-monthly by Prime National Publishing Corp. Focus on hospice and palliative care news and research. Website: <http://www.pnpco.com>

Cancer Care News – provides information for people with cancer, their families and loved ones. Website: <http://www.cancercare.org>

Cancer Pain Release – a quarterly publication of the World Health Organization Collaborating Center for Policy and Communications in Cancer Care. Website: <http://www.whocancerpain.wisc.edu/>

Cancer Pain Update – a quarterly newsletter of the Wisconsin Pain Initiative. Website: <http://www.wisc.edu/wcpi> or e-mail: wcpi@facstaff.wisc.edu

Clinical Journal of Pain – Official Journal of the American Academy of Pain Medicine

– A quarterly journal that provides information on all aspects of pain including the psycho-social dimensions and ethical issues of pain management. Website: <http://www.clinicalpain.com>

The European Journal of Palliative Care – Official journal of the European Association for Palliative Care. Published six times a year by Hayward Medical Communications. Website: <http://www.ejpc.co.uk>

Headway Migraine – a complimentary newsletter specifically focused on migraine and its treatment. To subscribe, contact website <http://www.imitrex.com/coping/headway.html>

Hospice Journal – Official journal of the National Hospice and Palliative Care Organization (NHPCO) which promotes and maintains quality care for the terminally ill and their families. Website: <http://www.haworthpressinc.com/>, e-mail: getinfo@haworthpressinc.com

HOSPICE Magazine – A quarterly magazine dedicated to promoting hospice care and end-of-life care issues. Website: <http://www.nhpc.org>

The Hospice Professional – a quarterly publication for members of the National Council of Hospice Professionals. This newsletter emphasizes hospice care and the interdisciplinary team concept. Each issue focuses on a theme. Website: <http://www.nhpc.org>

IASP Newsletter – International Association for the Study of Pain (IASP). Timely topics in pain research and treatment selected for publication as well as information on upcoming international and national conferences. IASP also publishes *Clinical Updates*, which provide periodic supplements devoted to specific pain conditions and related research. Website: <http://www.iasp-pain.org>

Innovations in End-of-Life Care – An on-line international peer-reviewed journal and forum highlighting promising practices that improve end-of-life care. Website: <http://www.edc.org/lastacts>, e-mail: inteleoljournal@edc.org/

International Journal of Pain Medicine and Palliative Care – An electronic newsletter featuring articles and reports from international medical venues and symposia, drawing together diverse work and palliative care literature. Website: <http://www.remédica.com/pain>

International Journal of Palliative Nursing – A bi-monthly publication which promotes excellence in palliative nursing. Website: <http://www.markallengroup.com>, e-mail: mark.allen_publishing@compuserve.com

IPOS Newsletter – The International Psycho-Oncology Society's (IPOS) membership is global and has international discourse to enrich the understanding of psycho-oncologic issues. Website: <http://www.ipos-aspboa.org>

Journal of Hospice and Palliative Nursing – A quarterly peer-reviewed journal published by NurseCom, Inc. Website: <http://www.HPNA.org>, E-mail: HPNA@hpna.org

Journal of Palliative Care – A quarterly publication that focuses on issues surrounding palliative care. Website: <http://www.allenpress.com>, e-mail: marcot@ircm.umontreal.ca

Journal of Palliative Medicine – The journal covers the team approach to palliative medicine, pain and symptom management, palliative-care education, legal, ethical, and reimbursement issues, and more. Website: <http://www.liebertpub.com>, e-mail: info@liebertpub.com

Journal of Pain and Symptom Management – Monthly journal that publishes original articles and other clinical papers. Website: <http://www.elsevier.com/locate/jpainsymman>

Journal of Psychosocial Nursing – Covers current news in psychosocial nursing, updates on psychopharmacology, geopsychiatry, and mental health nursing. Website: <http://www.psychnurse.org/>

LAST ACTS: Care and Caring at the End of Life – Published quarterly by the Robert Wood Johnson Foundation. Website: <http://www.lastacts.org>

LIFELINE – The Newsletter of the National Chronic Pain Outreach Association. (NCPOA). Lifeline welcomes reader correspondence and submissions of articles, book reviews, commentaries, cartoons, artwork, and poetry. Website: <http://neurosurgery.mgh.harvard.edu/ncpainoa.htm> or e-mail: ncpoa@cfw.com

NCCN Advantage – National Comprehensive Cancer Network (NCCN). Outlines current programs, conferences, and programs. Website: <http://www.nccn.org>

NCCS Networker – A quarterly publication of the National Coalition for Cancer Survivorship (NCCS). Provides information about NCCS activities and survivorship issues. Website: <http://www.cansearch.org> or e-mail: info@cansearch.org

THE NETWORK NEWS – A quarterly newsletter for healthcare professionals published by the Network Project at Memorial Sloan-Kettering Cancer Center in New York. Content includes a variety of topics related to cancer care including literature abstracts of current research studies, brief clinical articles, position postings and a calendar of conferences.

NHPCO Newsline – National Hospice and Palliative Care Organization sponsored newsletter published bi-weekly which details the activities of NHPCO and provides a calendar of events along with updates on legislative issues that may impact hospice care. Website: <http://www.nhpco.org/>

NYSCAPI News – New York State Cancer and AIDS Pain Initiative (NYSCAPI). Part of NYSCAPI's goal is to educate health care professionals, patients, and families affected by cancer and AIDS about the management of pain; to develop research that permits better management of pain; and to monitor legislation that might influence clinical management of pain. Website: <http://www.cancercare.org>, e-mail: info@cancercare.org/

PAIN – Official publication of the International Association for the Study of Pain. Website: <http://www.iasp-pain.org> or e-mail: iasp@locke.hs.washington.edu

Pain Medicine – Official Journal of the American Academy of Pain Medicine. Published 4 times a year by Blackwell Science, Inc. Website: <http://www.painmed.org/productpub/journal.html>

Palliative Medicine – International journal, published bi-monthly, dedicated to improving knowledge and clinical practice in the palliative care of patients with advanced disease. Website: <http://www.healthworks.co.uk>, E-mail: arnold@hodder.mhs.compuserve.com

Palliative & Supportive Care – a new international journal of palliative medicine that focuses on the psychiatric, psychosocial, spiritual, existential, ethical, and philosophical aspects of palliative care. It will be published starting in 2003. Website: <http://www.cambridge.org/>

PDIA Reader – An interesting and easily accessible source of recent articles on end-of-life issues. Published by the Project on Death in American (PDIA). Also offers proceedings from the 1st national conference on death and dying in prisons and jails: caring for prisoners, families, and caregivers. Website: <http://www.soros.org/>

Progress in Palliative Care – Multidisciplinary journal that provides information on all aspects of palliative care. Website: <http://www.leeds.ac.uk/lmi/ppc/ppcmain.html>, e-mail: maney@maney.co.uk

Psycho Oncology – Quarterly journal concerned with the psychological, behavioral, and ethical aspects of cancer. Website: <http://www.wiley.com>, e-mail: cs-journals@wiley.co.uk

Reflections – Prepared by The Program for Ethics at Oregon State University. Contains essays by leading participants in public debate regarding legalized assisted suicide. E-mail: pese@orst.edu

SCCPI Newsletter – A newsletter from the Southern California Cancer Pain Initiative that provides individuals with information on pain related items and upcoming meetings. Website: <http://sccpi.coh.org/>, e-mail: sccpi@coh.org

Supportive Care in Cancer – Provides members of the Multinational Association of Supportive Care in Cancer (MASCC) the most recent scientific and social information on aspects of supportive care for cancer patients at all stages of the disease. Website: <http://link.springer-ny.com/link/service/journals/00520/index.htm>, e-mail: custserv@springer-ny.com

D. PowerPoint Slide Sets

ASCO

American Society of Clinical Oncology Curriculum: Optimizing Cancer Care – The Importance of Symptom Management Syllabus & Slide Sets: American Society of Clinical Oncology (ASCO), 435 N. Michigan Avenue, Suite 1717, Chicago, IL 60611,

312-644-0878, 312-644-8557 FAX. Order through Kendall Hunt at
<http://www.kendallhunt.com> (search for ASCO when you get to the website)

W

American Society for Psychosocial and Behavioral Oncology/AIDS:
Online Lectures addressing Common symptoms among cancer patients. Available at
website: <http://www.ipos-aspboa.org/multimedia>
Assessment and Management of Common Symptoms in Cancer Patients by Deanne
Wolcott, MD
Psychosocial and Palliative Care Program: Emphasis on Cancer-Related Fatigue by P.
Jacobson, PhD.
Screening for Depression in a Large Ambulatory Oncology Network by Steve Passik,
PhD.
Cancer Pain Management at Cedars-Sinai Comprehensive Cancer Center by Tom
Strouse, MD.
Integrating Psychosocial and Palliative Care into Oncology Practice by Michael
Weitzner, MD.

W

Beth Israel Medical Center
Topics in Pain Management: A Slide Compendium. Visit Beth Israel Medical Center
website at: http://www.stoppain.org/for_professionals/compendium/

W

Cancer Pain Education for Patients and the Public (CPEPP) Training Program Slides
A program conducted from 1997 to 2001 by City of Hope investigators (Betty Ferrell,
Marcia Grant, and Gloria Juarez) funded by the National Cancer Institute. This
project was designed to address the multiple opportunities for cancer pain education
and to provide resources for successful implementation. The project materials on this
site include outlines, PowerPoint presentations, handouts and a comprehensive
bibliography for each module. (To download see Section III. Patient Education, C.
Educational Materials, Item 31)

Homecare Outreach for Palliative Care Education (HOPE) Training Program Slides
Slides available from the HOPE training program. A CD-ROM is included with your
order when you request a copy of the HOPE training program (To download the
order form for the HOPE curriculum, please see Section XI. End of Life/Palliative
Care, C. *Educational Materials/Curriculum*, Item 1).

Illinois Cancer Pain Initiative: Cancer Pain Can Be Relieved
A 25-slide set with narrative script designed for presentation to the general public.
Send check payable to: Illinois Cancer Pain Initiative, P.O. Box 6794, Villa Park, IL
60181, (800) DUL-PAIN.

Memorial-Sloan Kettering Cancer Center and Psychiatry Services:
Cancer Pain: Principles of Assessment, by Russell Portenoy, MD and Nathan Cherny,
MBBS, FRACP
Cancer Pain Syndromes, by Russell Portenoy, MD and Nathan Cherny, MBBS,
FRACP.
Opioid Pharmacotherapy of Cancer Pain, by Russell Portenoy, MD.

The Use of Adjuvant Analgesics in Cancer Pain, by Russell Portenoy, MD.
 The Use of Nonopioid and Adjuvant Analgesics in Cancer Pain, by Russell Portenoy, MD.
 Psychiatric Aspects of Cancer Pain Management, by William Breitbart, MD.
 Psychiatric Aspects of HIV/AIDS Pain, by William Breitbart, MD.
 The Assessment and Syndromes of Pain in HIV/AIDS, by William Breitbart, MD.
 The Treatment of Pain in HIV/AIDS, by William Breitbart, MD.
 Teaching modules developed by the faculty of the Network Project includes a lecture with references and 25-40 color slides. Each module costs. To order: indicate title of each teaching module and the number of copies. Make check payable to: The Network Project, CC 5112, Fund 7045”, Send to: The Network Project, 1275 York Avenue, New York, NY 10021, (212) 639-3164, (212) 752-7185 FAX

Emergency Room Information

Section Description: This section includes a bibliography of 11 references.

- A. *City of Hope Publications*
- B. *Recommended Books*
- C. *Educational Materials/Curriculum*
- D. *Guidelines/Clinical Pathways*
- E. *Other Organizational Links*
- F. *Key References*

Bibliography

W 11 current references to pain management in the emergency room (2002 version)

- G. *Position Statements/Standards*

Headache Information

- A. *City of Hope Publications*
- B. *Recommended Books*

The Child with Headache: Diagnosis and Treatment by Patricia A. McGrath and Loretta M. Hillier (2001). ISBN: 0-931092-30-2. IASP Press. Website: <http://www.iasp-pain.org/>

- C. *Educational Materials/Curriculum*
- D. *Guidelines/Clinical Pathways*
- E. *Other Organizational Links*

American Council for Headache Education

<http://www.achenet.org>

American Pain Society

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

National Headache Foundation

<http://www.headaches.org>

- F. *Key References*

Resource List

W - 3 page listing of organizations and resources

Health Facts for You – University of Wisconsin – 1999 version
 Information sheet on migraine headaches

W

G. Position Statements/Standards

Non Drug Pain Interventions

Section Description: This section includes several hand-outs for non-drug management of pain at home. In addition, bibliography on various techniques and resources are available.

A. City of Hope Publications

B. Recommended Books

W

Pain: Clinical Manual 2nd Edition by McCaffery & Pasero, 1999 book order form - this manual is an invaluable guide to an interdisciplinary approach in the care of patients with pain. ISBN #: 0-8151-5609-X (29563). Visit <http://www.mosby.com> to order. (enter ISBN # or search for pain on website to find this item)

C. Educational Materials/Curriculum

W

Academy for Guided Imagery

Interactive guided imagery self paced audio/video study course, P.O. Box 2070, Mill Valley, CA 94942, 1-800-726-2070, 415-389-9324, 415-389-9342 FAX, Website: <http://www.interactiveimagery.com>

W

The Art of Caring -

Nurses and caregivers are at the forefront of the healthcare revolution. Join three experts in holistic nursing for this complete course in total mindbody healthcare, including alternative techniques based on imagery, music, touch, subtle energy, and more. *The Art of Caring* is for nurses, therapists, hospice workers, counselors, doctors - anyone interested in creating "whole-person" health. Nurses can earn 9.6 contact hours for completing the accompanying 40-page workbook. Product code: 1-56455-302-7. Order form available at <http://store.yahoo.com/soundstrustore/af00023.html>

Coping Skills for Bone Marrow Transplantation

Relaxation, imagery, distraction and conversation with yourself (e.g., positive thoughts). These approaches to pain management are helpful with pain experiences other than bone marrow transplantation. To order booklet and accompanying audio tape for relaxation: Behavioral Sciences, Fred Hutchinson Cancer Research Center, 1100 Fairview Avenue N., FM815, Seattle, WA 98109-1024, (206) 667-5022, (206) 667-6356 Fax

W

Core Curriculum for Holistic Nursing – 1997 version

Based on AHNA's Standards of Holistic Nursing Practice. Barbara M. Dossey, RN, MS, HNC, FAAN. 1997, 416 pages. Published by Aspen Publishing. ISBN #0834208709. Order online at <http://www.aspenpublishers.com/> (to find this item search for core curriculum on website) or call toll-free 1-800-638-8437.

W Exceptional Cancer Patients
This is a healing center founded by Bernie Siegel, MD, which sells self-help materials and audiotapes, including relaxation tapes. Touch Star Productions, 522 Jackson Park Drive, Medville, PA 16335, (800) 759-1294, (814) 337-0699, Website: <http://www.touchstarpro.com> , e-mail to kcb@touchstarpro.com

W Graceful Passages
Interfaith audio resource (CD) to assist caregivers, dying persons, and their families to help transition from denial to acceptance. To order: Companion Arts, P.O. Box 2528, Novato, CA 94948-2528, (415) 209-9408, (888) 242-6608, Website: <http://www.gracefulpassages.com> , E-mail: music@gracefulpassages.com

W Holistic Nursing, a Handbook for Practice, 3rd Edition - 2000
For all nurses who are interested in gaining in-depth knowledge of holistic nursing. Learn how to use safe, cost-effective holistic nursing interventions to complement medical and surgical techniques. With ample use of case studies, step-by-step techniques, and practical tools incorporating an overall vision of holistic healing, this vital handbook gives you a firm theoretical foundation and skills for applying new holistic caring modalities. For nurses in all settings-critical care, home health, clinic, and classroom. An instructor's manual is available upon request. ISBN #0834216299. Order online at <http://www.aspenpublishers.com>

W Instructor's Manual for Holistic Nursing: A Handbook for Practice
Prepared by Barbara M. Dossey, RN, MS, HNC, FAAN, Cathie Guzzetta, RN, PhD, FAAN, and Lynn Keegan, PhD, RN, FAAN, 88 pages. Published by Aspen Publishing. ISBN # 0834217007. Call 1-800-638-8437 to order.

W Fast Fact – 5 Minute Inservice
Nonpharmacologic (Mind – Body) Approaches to Managing Pain

D. Guidelines/Clinical Pathways

E. Other Organizational Links

American Academy of Medical Acupuncture <http://www.medicalacupuncture.org/>

American Association for Therapeutic <http://www.aath.org>

Humor

American Holistic Nurses Association <http://www.ahna.org>

American Massage Therapy Association <http://www.amtamassage.org>

American Music Therapy Association <http://www.namt.com>

Internet Health Library <http://www.internethealthlibrary.com>

National Center for Complementary and <http://nccam.nih.gov>

Alternative Therapies

Simonton Center <http://www.simontoncenter.com>

F. Key References

Packet of Non-Drug Information

- Rhiner M, Ferrell BR, Ferrell BA, Grant MM. "A Structured Nondrug Intervention Program for Cancer Pain." *Cancer Practice*, 1993; 1(2):137-143 - The purpose of this article is to report on the development and initial results of nondrug interventions used in a pain education program for elderly cancer patients at home. The nondrug methods include heat, cold, massage/vibration, distraction, and relaxation, with 19 interventions described.

W Patient Education Program (English & Spanish versions). Descriptive hand-outs offering detailed instructions on the 19 non-drug interventions featured in the above article "A Structured Nondrug Intervention Program for Cancer Pain." These instruction guides were incorporated into an entire workbook on managing cancer pain at home. The modalities featured include: Massage (Hand, Vibration), Distraction (Music, Humor), Relaxation (Imagery, Breathing Exercises, and Tapes), Cold (Ice Bags, Cold Cloth, Frozen Gel Packs, Ice Massage), and Heat (Heating Pad, Hot Baths, Moist Heat, Hot Wrap). A list of research publications based on studies at the City of Hope which led to the development of this patient teaching project.

W Non-Drug Bibliography (2001 version)

W Non-Drug Resource List (1998 version)

W Music as Medicine – Bibliography

G. Position Statements/Standards

AHNA Standards of Holistic Nursing: Guidelines for Caring and Healing – 2000 version

W

The Standards of Holistic Nursing Practice and how they are applied in daily practice. Order form available at <http://www.aspenpublishers.com>

California Board of Registered Nursing Complementary and Alternative Therapies in Registered Nursing Practice – 2000 version

W

The competency of a registered nurse to perform the skills of complementary and alternative therapies begins with nursing education and end with the safe nursing practice of those skills in such a way "that ensures the safety, comfort, personal hygiene, and protection of patients; and the performance of disease prevention and restorative measures". Download at <http://www.rn.ca.gov>

Oncology Nursing Society Position Statement on Complementary and Alternative Therapies – 2000 version

W

The interchangeable use of the terms "complementary", "alternative", and "integrative" therapies has contributed to confusion and misconceptions in addressing this domain of treatment. These terms do not necessarily describe what a therapy may be but, rather, how it is used. This statement will further discuss the difference between these terms and what the duty of the oncology nurse is in using these therapies. Download at <http://www.ons.org>

CITY OF HOPE ORDER FORM

Total number of materials: _____
Total amount of order: _____
Add \$15.00 for orders mailed overnight: _____

Please note: Please print each page where items are requested from the Index/Order Form and include with the check and this ORDER FORM. We must receive payment with the order. We are unable to send an invoice, accept Purchase Orders or credit card charges. We are able to accept payment in U.S. currency only.

Make check payable to: City of Hope National Medical Center

Mail check and order form to: City of Hope National Medical Center
City of Hope Pain/Palliative Care Resource Center
c/o Nursing Research and Education
1500 East Duarte Road
Duarte, CA 91010

CUSTOMER INFORMATION (*mailing address to receive materials*)

Name _____

Institution _____

Address _____

City _____ State _____ Zip Code _____

Phone _____

For our Records: How did you hear about us?

_____ Ad in a journal/newsletter _____ At a conference
_____ Received an index/order form in mail _____ A colleague
_____ Internet Search _____ Other (list: _____)

Profession:

___ RN ___ MD ___ Soc. Work ___ Pharm
___ Patient ___ Family Member ___ PT/OT ___ Other (list: ___)

Work setting:

Hospital Hospice Home Care Clinic/Outpt.
 Nursing Home/Long Term University Other (list: _____)

Web Site:

- 1) Have you used the PRC website (<http://prc.coh.org>)? _____ Yes _____ No
- 2) What was the most useful feature of the web site? Do you have any suggestions to enhance it?



ENDOMETRIOSIS ASSOCIATION, INTERNATIONAL

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
<i>Endometriosis: The Inside Story</i>	Video on endo including stories		U.S. \$29.95
<i>Endometriosis & Dioxins: What every Gynecologist should know.</i>	Free brochure		
Note that the items mentioned under patient education/public awareness are also suitable for professional education.			

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
<i>The Endometriosis Source Book (1995)</i>	Current treatment options, latest research, common myths about the disease, coping strategies-physical and emotional.	474	US \$14.95
<i>Overcoming Endometriosis: New Help for the Endometriosis Association (1987)</i>	Anthology of acclaimed articles, fact sheets, research reviews, etc. Treatments, strategies, new directions, research recaps.	329	US \$14.95
<i>Endometriosis: A Key to Healing Through Nutrition (1999)</i>	Explanation of endometriosis affects on the body, advise on pain reduction and improved fertility, the role of nutrition, information on foods that harm, health, vitamins and minerals, recipes and menus, cast histories.	404	US \$16.95

Various expert videos/tapes/cds on aspects of the disease from anniversary conferences.	Bowel endometriosis; laparoscopically assisted vaginal hysterectomy for endo; when is laparotomy appropriate?; what's new in preventing adhesions?; infertility and endo; endometriosis : What a pain it is; nutrition and endo: does endometriosis run in the family?; coping with endo; traditional Chinese medicine and endo; national vs. synthetic hormones; Hispanics women and endo; black women and endo; husbands, partners, families and friend and endo. Overview: do we really know what about endometriosis? New finding on candidiasis and endo; Living with an overcoming endo.		Cost vary
Endometriosis: Diagnostic Kit			US \$4.75
<i>Teens Speak out on Endometriosis</i>	First video where teens with endo tell their stories. Diagnosis, treatment, coping and sources for help are included		US \$145.95
Free brochures on: Endometriosis and the work of the Association (28 languages) Endometriosis for teenagers "Killer Cramps"—pain Various free brochures on Endo and Environmental toxins including dioxin, phthalates			

Facts and Figures on Endometriosis In Spanish, English, French. Including from vulnerable groups of women. Free

Name: Endometriosis Association, International Headquarters
Address: 8585 North 76th Place, Milwaukee, WI 53223, USA
Phone: Toll Free – 800-992-3636; (414) 355-2200
Email: endo@endometriosisassn.org
Web Site: www.EndometriosisAssn.org



FOR GRACE

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
RSD/CRPS	Clinical Guidelines	5	Free

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
RSD Brochure	Information on RSD	1	Free
RSD/CRPS by Dr. Edward Canden	Layman guideline	5	Free

Contact: John Garrett
 Name: For Grace
 Address: Post Office Box 1724, Studio City, CA 91614
 Phone: 818-760-7635
 Email: rsdaware@forgrace.org
 Web Site: www.forgrace.org



National Pain Foundation

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
“Untying the Knot”	Pain Awareness symbol - Lapel Pin		\$2.50 each
NPF Brochure	Web site description	3 fold brochure	N/C
Pain Ambassador Power Point Presentation	For speaking with communities about the issues in the pain industry	20 Slides	N/C

Please let us know how to place the order or learn more about your resources.

Contact: National Pain Foundation
 Name: Mary Pat Aardrup
 Address: 3070 South Williams Street - Denver, CO 80210
 Phone: 303/756-0889
 Email: aardrup@painconnection.org

Thank you!



National Women’s Health Resource Center

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
Pain management	Overview, questions to ask your health provider, resources,		
	quiz	Healthywomen.org Website/print version available	free

Contact: Vivien Ngethe
 Address: NWHRC 120 Albany Street
 Phone: 732.828.8575 or toll free at 1.877.986.9472
 Email: vngethe@healthywomen.org



INTERSTITIAL CYSTITIS

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
ICA Healthcare Provider Fact Sheet Series—on plain white paper, suitable for photocopying.	Our Fact Sheet series is available in sets containing all 19 Fact Sheets including: Bladder Retraining Program; Children & IC; Cystoscopy & Hydrodistention; IC & Constipation; Cystistat®; DMSO; Elmiron®; Heparin; Hydroxyzine; IC & Other Diseases; IC & Men; IC & Pregnancy; Social Security Disability Issues; Surgical Procedures; Tricyclic Antidepressants; The Potassium Sensitivity Test; IC & Pain, InterStim Therapy; and the NEW ICA Treatment Guidelines.	19 Fact sheets, some of which are 2 or 3 pages	\$6.50 per packet of 19 Fact Sheets
Interstitial Cystitis Brochure	Overview of the disease & treatments	4-panel 2-color brochure	6.25 per pack of 25 each
Interstitial Cystitis Brochure	Same brochure—in Spanish	4-panel 2-color brochure	6.25 per pack of 25 each
IC & Diet	Description of how diet may affect IC and what foods and beverages may or may not be involved.	4-panel 2-color brochure	6.25 per pack of 25 each
IC & Sexuality	Description of how IC may affect the ability of IC patients to enjoy their sex lives, Offers suggestions and alternatives for those who find traditional sex too painful.	4-panel 2-color brochure	6.25 per pack of 25 each
IC & Self-Help	Descriptions of techniques that patients can try on their own to help alleviate their symptoms.	4-panel 2-color brochure	6.25 per pack of 25 each
Men & IC	Description of how IC affects men as well as which treatment and self-help measures may work for them.	4-panel 2-color brochure	6.25 per pack of 25 each

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
Interstitial Cystitis Brochure	Overview of the disease & treatments	4-panel 2-color brochure	6.25 per pack of 25 each
Interstitial Cystitis Brochure	Same brochure—in Spanish	4-panel 2-color brochure	6.25 per pack of 25 each
IC & Diet	Description of how diet may affect IC and what foods and beverages may or may not be involved.	4-panel 2-color brochure	6.25 per pack of 25 each
IC & Sexuality	Description of how IC may affect the ability of IC patients to enjoy their sex lives, Offers suggestions and alternatives for those who find traditional sex too painful.	4-panel 2-color brochure	6.25 per pack of 25 each
IC & Self-Help	Descriptions of techniques that patients can try on their own to help alleviate their symptoms.	4-panel 2-color brochure	6.25 per pack of 25 each
Men & IC	Description of how IC affects men as well as which treatment and self-help measures may work for them.	4-panel 2-color brochure	6.25 per pack of 25 each
ICA Treatment Guidelines	A comprehensive outline of the treatments and medications currently recommended for IC, including diagnostic techniques and medications in developments. A must-have for newly diagnosed patients and their healthcare providers	4 full-size 2-color glossy pages	1.50 each
ICA Treatment Guidelines	Same publication-in Spanish	4 full-size 2-color glossy pages	1.50 each
ICA Fact Sheet: Finding the Right Physician For You	A very informative fact sheet on how to select a physician to collaborate with you on treating your IC	1 page printed 2 sides	1.00 each

Log onto www.ichelp.org; click on *Physician Resources*. All of the ICA’s resources for Healthcare Providers are listed here and available to order on-line. OR call 1-800-HELP ICA and ask for a Healthcare Provider Order Form.

Contact: Interstitial Cystitis Association
 Name: Ann Moritz Chesnut, Director of Communications
 Address: 110 North Washington Street, Suite 340, Rockville, MD 20850
 Phone: 301-610-5300
 Email: ICAmail@ichelp.org
 Web Site: www.ichelp.com



LUPUS FOUNDATION OF AMERICA

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Item Number	Charge
What is Lupus?	Brochure	B0001	\$30 per 100
Joint & Muscle Pain in Systemic Lupus Erythematosus (SLE)	Brochure	B0017	\$25 per 100
Dolor en las Articulaciones y los Musculos Producidos por el Lupus (Joint & Muscle Pain)	Easy to read fact sheets-Spanish	FSE008	\$25 per 100
Que es le Lupus (What is Lupus?)	Easy to read fact sheets-Spanish	FSE0012	\$25 per 100

Contact: Lupus Foundation of America
 Name: Dorothy K. Howe, Vice President of Education
 Address: 1300 Piccard Drive, Rockville, MD 20850-4303
 Phone: 301-670-9486
 Email: home@lupus.org

Order Information:
 LFA – P.O. Box 932615
 Atlanta, GA 31193-2615

 Toll Free: 866-4-THE-LFA or
 866-484-3532



MEN'S HEALTH NETWORK

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
MHN Health Zone	Turnkey Health Fair Kit		
Get It Checked	Screening Guidelines for men & women	1	\$0.35 each
Facts About Prostrate Cancer		1	\$0.35 each
Facts About Low Testosterone			\$0.35 each
Shower Hangers card. Breast self-exam on one side/testicular self exam and prostate information on other side			\$1.25 each
Screening and Event Planner	Designed to help you create screening projects. Step by step planning guide and CD-Rom documents		\$125
19 Ways to save your husband's life.	11" x 17" card		\$0.50

Contact: Ryan Cooper
 Name: Men's Health Network
 Address: Post Office Box 75972, Washington, DC 20013
 Phone: 202-543-6461
 Email: order@menshealthnetwork.org
 Web Site: www.menshealthnetwork.org



NATIONAL HEADACHE FOUNDATION

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
The Emergency Room Guide to Distinguishing the Legitimate Headache Sufferer from the Drug Seeking Patient			Free on www.headaches.org
Headache Screening Questionnaire	Use this helpful screening tool to get valuable information from your patients		Free on www.headaches.org
Headache Measurement Tools	Accurate measurement and better communication of headache impact on a patient's life are the goal of these measurement and assessment tools .		Free on www.headaches.org
Migraine Prevention Screening Tool	A brief questionnaire designed to help an individual determine if they need migraine prevention treatment.		Free on www.headaches.org

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
Newsletter			
Headache Measurement Tools	Learn how headache impacts your life.		Free on www.headaches.org
Patient Assistance Programs	Some pharmaceutical companies make medications available at no charge to eligible patients.		Free on www.headaches.org
Ten Important Steps	Leading headache specialists recommend specific steps migraine sufferers can take to better communicate with their healthcare providers and obtain a successful treatment program.		Free on www.headaches.org
Headache F.A.Q.	Frequently asked questions about headaches.		Free on www.headaches.org
Headache Topics	Each sheet is brief yet packed with important info.		Free on www.headaches.org

<u>NHF Headache Fact Sheet</u>	The NHF Headache Fact Sheet is a quick reference for anyone who wants to know more about the effects of headache.		Free on www.headaches.org
<u>Headache Measurement Tools</u>	Learn how headache impacts your life.		Free on www.headaches.org
<u>Headache Screening Questionnaire</u>	Use this helpful screening tool to learn valuable information about headaches		Free on www.headaches.org
<u>Headache Diary</u>	Keeping detailed records of headache episodes can help provide additional insight about triggers and how to avoid them.		Free on www.headaches.org

Contact: National Headache Foundation

Name: Suzanne Simons

Address: 820 N. Orleans, Suite 217, Chicago, IL 60610

Phone: 888-NHF-5552

Email: info@headaches.org

Web Site: www.headaches.org

BROCHURES		
<i>(Prices require additional postage of \$2.00 for 11–20 pieces and \$3.00 for 21–75 pieces. Orders for 76 pieces or more will be charged exact postage. Please call for more information.)</i>		
	NHF Member	Non- Member
<p style="text-align: center;">The Complete Headache Slide Chart</p> <p>Chart lists 21 different types of headaches, their symptoms, precipitating factors, treatment and prevention.</p>	\$2.00	\$2.50
<p style="text-align: center;">The Headache Handbook</p> <p>8-page brochure with information on causes, types of headaches, available treatments</p>	\$1.00	\$1.50
<p style="text-align: center;">About Headaches</p> <p>16-page pamphlet with in-depth look at headaches, tips on when to seek medical advice, treatment, etc.</p>	\$1.25	\$1.75
<p style="text-align: center;">About Stress Management</p> <p>16-page brochure underscores the health benefits that come from managing stress effectively. It identifies stress-management techniques, talks about how to get started and where to locate additional help for managing stress.</p>	\$1.25	\$1.75
<p style="text-align: center;">About Relaxation Techniques</p> <p>16-page brochure overview includes step-by-step instructions for do-it-yourself relaxation method such as meditation, deep-breathing, and visualization. It also includes background information on massage, yoga, and other techniques.</p>	\$1.25	\$1.75
<p style="text-align: center;">About Over-the-Counter Medications</p> <p>16-page brochure explains the importance of using OTC medications properly, the potential risks and precautions to take with certain medications, how to read medication labels, and other valuable patient information.</p>	\$1.25	\$1.75
<p style="text-align: center;">How to Talk to Your Doctor</p> <p>8-page brochure on when to seek help for a headache problem, keeping a headache diary, discussing headache with your doctor.</p>	\$1.00	\$1.50
<p style="text-align: center;">A Patient's Guide to Migraine Prevention & Treatment</p> <p>10-page guide includes causes and phases of migraine, drug and non-drug approaches to treatment and prevention, and a diet for migraine sufferers.</p>	\$1.00	\$1.50

<p>Headache: A Guide to Prevention & Treatment 6-page guide covers topics such as the different types of headache; drug and non-drug therapy; when and how to discuss your headache symptoms with your doctor.</p>	\$1.00	\$1.50
<p>Alternative Therapies & Headache Care 20-page brochure intended as an introduction to alternative medicine, this publication would guide you through the vast array of alternative headache remedies. The goal of the booklet is to further the principle that an informed consumer more effectively participates in personal healthcare decisions.</p>	\$3.00	\$4.00
<p>Managing Headaches: What You Need to Know 88-page guide to the Standards of Care for Headache Diagnosis and Treatment as established by the National Headache Foundation.</p>	\$4.00	\$5.00
<p>New perspectives on caffeine and headache: Straight talk for headache sufferers 19-page brochure summarizes and explains the most recent information about the unique relationship between caffeine and headache.</p>	\$3.00	\$3.50
<p>The Relaxation Tape Audiotape teaches techniques for greater self-control and relaxation. Narrated by a physical therapist, tape contains a 30-minute and 15-minute sessions.</p>	\$9.00	\$12.00
<p>Stretch and Relax Tape Audiotape based on series of progressive relaxation techniques involving tightening and relaxing of specific muscle groups; contains 30-minute and 15-minute sessions.</p>	\$11.00	\$14.00
<p>(New) Relief from Tension-Type Headaches: Unique Medication-Free Techniques... Effective Results. This educational videotape demonstrates easy strategies for managing neuro-musculo-skeletal problems of the neck, shoulder, and scapular regions, which can contribute to tension-type headaches. Video runs 28 minutes.</p>	\$14.95	\$17.95

BOOKS	NHF Member	Non- Member
(Prices include postage & handling)		
<p>Migraines: Everything You Need to Know About Their Cause and Cure <i>Arthur H. Elkind, M.D.</i> 250-page paperback book with information on migraine causes and triggers; migraines in women, children and adolescents; treatment approaches; non-drug therapies; and resource listings.</p>	\$7.95	\$9.95
<p>Headache Relief <i>Seymour Diamond, M.D., Bill Still & Cynthia Still</i> 219-page book based on the latest headache research. New insight into what can be done for migraine, tension-type, and food-related headaches.</p>	\$10.95	\$13.95
<p>Headache in Children <i>Leonardo Garcia-Mendez, M.D.</i> 184-page book by a pediatric neurologist providing practical information for parents, teachers, and caregivers.</p>	\$16.95	\$19.95
<p>Headache Help: A Complete Guide to Understanding Headaches and the Medicines That Relieve Them (2nd Edition Updated and Revised) <i>Lawrence Robbins, M.D. & Susan S. Lang</i> 320-page book with extensive sections on new medication treatments, as well as non-medicine therapies; including an extensive herbal and alternative section.</p>	\$18.00	\$21.00
<p>Making Control of Your Headaches: How to Get the Treatment You Need <i>Paul N. Duckero, Ph.D., William D. Richardson, M.D., and Janet E. Marshall, R.N.</i> 178-page book discusses coordination of medications, physical therapy, and behavioral changes to address all factors contributing to headache.</p>	\$17.95	\$20.95
<p>(NEW) Conquering Your Migraine Seymour Diamond, M.D. with Mary A. Franklin 224-page essential guide to understanding and treating migraines for all sufferers and their families.</p>	\$16.00	\$19.00
<p>(NEW) Headache and Your Child <i>Seymour Diamond, M.D., and Amy Diamond</i> 254-page complete guide to understanding & treating migraine & other headaches in children & adolescents. There is a patient history questionnaire, headache calendar and list of patient resources.</p>	\$16.00	\$19.00

(NEW) The Migraine Gourmet <i>Jerry Rainville</i> 154-page guide to migraine-free cooking. Includes recipes from appetizers to desserts, as well as tips for navigating your way through the grocery store and when dining out.	\$15.95	\$18.95
(NEW) Therapeutic Guide for the Treatment of Headache 2000 248-page helpful guide aids physicians in prescribing approved pharmaceuticals as well as drugs approved for other uses that may be helpful abortively and prophylactically to the headache sufferer. This guide is updated periodically as new information becomes available.	\$22.00	\$22.00
(NEW) Standards of Care for Headache Diagnosis & Treatment 80-page guideline establishes a set of standards to ensure comprehensive and consistent delivery of medical care for headache sufferers; setting forth criteria for diagnosis, treatment and hospitalization when medically indicated.	\$10.00	\$15.00
Outside of North America, please add \$3.00 postage. TOTAL		

Name _____ Member ID Number _____

Address _____ Daytime Phone _____

City _____ State _____ Zip _____ Email _____

Please make your check/money order payable to the National Headache Foundation, or charge:

VISA MasterCard American Express Discover

Card # _____ Expiration Date _____

Cardholder Name _____

Order by...Phone: **1 888 NHF 5552**
Fax: **773 525 7357**

Mail: **National Headache Foundation**
428 West St. James Place, 2nd Floor
Chicago, IL 60614



NATIONAL URBAN LEAGUE

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
Health Alert!	Health tips for mature workers (55+)	2	Free
The Mature Worker	Information on NUL-SCSP Program	4	Free

Contact: William Dawson, Program Coordinator, Public Information
Name: National Urban League Seniors In Community Service Program
Address: 120 Wall Street, 7th Floor, New York, NY 10005
Phone: 212-558-5441
Email: wdawson@nul.org
Web Site: www.nul.org



NATIONAL VULVODYNIA ASSOCIATION

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
NVA Research Update Newsletter	e-newsletter summarizing current research	Varies	None
NVA News	Printed newsletter containing articles on vulvar pain written by experts	12 pgs	\$60/year
Vulvodynia Teaching CD	Contains teaching presentation, self-help tips handout, resource list	30 min- 1 hour	\$30
NVA Brochure	Overview of condition	N/a	none

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
NVA Brochure	See above	N/a	None
NVA News	See above	12 pgs	\$40 (patients)
NVA Update	e-newsletter that alerts community of current news related to vulvar pain	Varies	None

Contact: National Vulvodynia Association

Name: Chris Veasley

Address: PO Box 4491, Silver Spring, MD 20914-4491

Phone: 301-299-0775

Email: chris@nva.org

Web Site: www.nva.org



THE NEUROPATHY ASSOCIATION

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
A Guide to the Peripheral Neuropathies	A listing of over 100 types of neuropathies	24 pages	\$15.00
Exercising with Neuropathy	Exercises for neuropathy	16 pages	\$10.00
Explaining Peripheral Neuropathy	Description of neuropathy	20 pages	\$10.00

*Medical professionals should visit www.neuropathymd.org for past CME meetings and topics covered.

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
Explaining Peripheral Neuropathy	Description of neuropathy	20 pages	\$10.00
Exercising with Neuropathy	Exercises for neuropathy	16 pages	\$10.00
Back issue of Neuropathy News (1 issue)	Newsletter containing articles on neuropathy	Varies per issue	\$3.00
Set of back issues of Neuropathy News (1-15)	Newsletter containing articles on neuropathy	Varies per issue	\$37.50
Membership brochure form	Form for becoming a member		Free
Relaxing with Neuropathy	Audio tape for relaxation	Audio tape	\$5.00
Facts about Neuropathy	Quick facts about neuropathy	1 page	Free
Questions often asked about Peripheral Neuropathy	Answers to common questions about neuropathy	1 page	Free

*Patients should visit www.neuropathy.org for more information on neuropathy.

Contact: Catherine Law
 Name: The Neuropathy Association
 Address: 60 East 42nd Street, Suite 942
 Phone: 212-692-0381
 Email: clawna@ix.netcom.com
 Web Site: www.neuropathy.org



POST POLIO HEALTH INTERNATIONAL

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
Information about the late effects of polio	In three sections: for polio survivors; for families and friends; for health professionals www.post-polio.org/inp/aboutlep.html	trifold	1-25 free 25-50 S & H 51-100 \$10 plus S & H
Post-Polio Syndrome: Identifying Best Practices in Diagnosis & Care	Summary of International Conference of Researchers and Clinicians in 2000.	25 pages	S & H
Post-Polio Health	Quarterly newsletter	12 pages	With membership \$25
Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors	Book on dictionary format www.post-polio.org/inp/hndbk99.html	120 pages	\$11.50 each
Information about ventilator-assisted living	Q & A format discussing the use of home mechanical ventilation. Will be online later	12 pages	1-25 free 25-50 S & H 51- 100 \$10 plus S& H
Ventilator-Assisted Living	Quarterly Newsletter	12 pages	With \$25 membership

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
Information about the late effects of polio	In three sections: for polio survivors; for families and friends; for health professionals www.post-polio.org/ipn/aboutlep.html	Trifold	1-25 free 25-50 S & H 51- 100 \$10 plus S& H
Post-Polio Health	Quarterly Newsletter	12 pages	With \$25 membership
Guidelines for people who had polio	Summary from 2000 International conference www.post-polio.org/inp/modp.html	Trifold	S & H

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors	Book in dictionary format	120 pages	\$11.50 each
Information about ventilator-assisted living	Q & A format discussing the use of home mechanical ventilation	12 pages	1-25 free 25-50 S & H 51- 100 \$10 plus S& H
Ventilator-Assisted Living	Quarterly Newsletter	12 pages	\$25 with membership

Contact: Post-Polio Health International

Name: Justine Craig-Meyer

Address: 4207 Lindell Boulevard, #110, Saint Louis, MO 63108

Phone:314-534-0475

Email: info@post-polio.org

Web Site: www.post-polio.org



REFLEX SYMPATHETIC DYSTROPHY SYNDROME ASSOCIATION OF AMERICA

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
Do you have RSD/RCPS?	Symptoms/diagnostic criteria	Formatted brochure	free
Clinical Practice Guidelines	Comprehensive Guidelines	46 pp.	\$1.60
RSD Review	Quarterly Newsletter	16-20 pp	\$15/year
Telltale Signs of RSD	10 Telltale Signs	Laminated card	free

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
Do you have RSD/RCPS?	Symptoms/diagnostic criteria	Formatted brochure	free
Clinical Practice Guidelines	Comprehensive Guidelines	46 pp.	\$1.60
RSD Review	Quarterly Newsletter	16-20 pp	\$15/year
Telltale Signs of RSD	10 Telltale Signs	Laminated card	free
Helping Children/Youth with RSD/CRPS Succeed in School		Tri-fold pamphlet	Free

Contact:

Name: Jim Broatch

Address: RSDS, Post Office Box 502, Milford, CT 06460

Phone: 203-877-3790

Email: jwbroatch@aol.com

Web Site: www.rds.org

RSDSA, with the assistance of Dr. Srinivasa N. Raja, co-chair of our scientific advisory committee and Director of Pain Research at Johns Hopkins University School of Medicine has produced a PowerPoint slide presentation on the *Diagnosis and Treatment Options of RSD/CRPS*. The slide kit is available for download on our website at www.rds.org. To view and utilize the slides, you must have Microsoft PowerPoint.



TRIGEMINAL NEURALGIA ASSOCIATION

We can offer the following materials for professional education:

Title	Summary of Contents	Pages/length	Charge
Trigeminal Neuralgia: A Primer for Physicians and Patients	Booklet containing information on TN, diagnosis- medical & surgical treatments	9 pages	\$1.50 to physicians
“Striking Back” The Trigeminal Neuralgia Patient Handbook	Comprehensive Overview of the disorder and related facial pain conditions written in layman terms	250 pages	\$13.95 + S&H \$3 ground \$5 priority

We can offer the following materials for public awareness/patient education:

Title	Summary of Contents	Pages/length	Charge
“Striking Back” The Trigeminal Neuralgia Patient Handbook	Comprehensive Overview of the disorder and related facial pain conditions written in layman terms	250 pages	\$13.95 + S&H \$3 ground \$5 priority
Trigeminal Neuralgia: AN Overview for Patients and Their Families		4 pages	Free
Trigeminal Neuralgia Encouragement	Information, support, encouragement brochure	Tri-fold	free

Contact: Trigeminal Neuralgia Association

Name:

Address: 2801 SW Archer Road, Suite C, Gainesville, FL 32608

Phone: 325-376-9955

Email: tnanational@tna-support.org

Web Site: www.tna-support.org



The American Chronic Pain Association Quality of Life Scale A Measure of Function for People with Pain

Pain is a highly personal experience. The degree to which pain interferes with the quality of a person's life is also highly personal.

The American Chronic Pain Association Quality of Life Scale A Measure of Function for People with Pain	
1 Non-functioning	<ul style="list-style-type: none"> ➤ Stay in bed all day ➤ Have no contact with outside world
2	<ul style="list-style-type: none"> ➤ Get out of bed ➤ Don't get dressed ➤ Stay at home all day
3	<ul style="list-style-type: none"> ➤ Get dressed in the morning ➤ Minimal activities at home ➤ Contact with friends via phone
4	<ul style="list-style-type: none"> ➤ Do simple chores around the house ➤ Can do minimal activities outside of home two days a week
5	<ul style="list-style-type: none"> ➤ Normal life at home ➤ Some outside activity ➤ Not able to work
6	<ul style="list-style-type: none"> ➤ Work part time ➤ No energy to do anything else
7	<ul style="list-style-type: none"> ➤ Work daily but it's very difficult ➤ Can make plans to do simple activities on the weekends
8	<ul style="list-style-type: none"> ➤ Work daily with some effort ➤ Have energy to make plans for one evening activity during the week ➤ Active on weekends
9	<ul style="list-style-type: none"> ➤ Work daily ➤ Take part in family life ➤ Outside activities very limited
10 Normal Quality of Life	<ul style="list-style-type: none"> ➤ Go to work each day ➤ Have a social life outside of work ➤ Take an active part in family
Copyright 2003 The American Chronic Pain Association	

The American Chronic Pain Association Quality of Life Scale looks at ability to function, rather than at pain alone. It can help people with pain and their health care team to evaluate and communicate the impact of pain on the basic activities of daily life. This information can provide a basis for more effective treatment and help to measure progress over time.

With a combination of sound medical treatment, good coping skills, and peer support, people with pain can lead more productive, satisfying lives. The American Chronic Pain Association can help.

For more information, contact the ACPA:
 Post Office Box 850
 Rocklin, CA 95677
 916.632-0922
 Fax: 916.632.3208
 E-mail ACPA@pacbell.net
 Web Page
www.theacpa.org