Community Recommendations for Appropriate, Humane Medical Care for Dying or Irreversibly Ill Patients

January 1997
Cure-oriented vs. comfort care
Medical interventions for dying or irreversibly ill patients can be described as either cure-oriented care or as comfort care. Specific procedures may fall into either of these categories. The distinction between them lies in the purpose of the intervention.

Cure-oriented interventions are those with the primary purpose of attempting to achieve a cure, reverse or stabilize the disease process, or bring about a meaningful and measurable improvement in the health status of the patient. These are often invasive procedures such as dialysis, ventilators and cardiopulmonary resuscitation (CPR) but may also include less invasive interventions such as intravenous hydration, antibiotics and diagnostic tests.

Comfort care (or palliative care) interventions have the primary purpose of alleviating distressing physical symptoms and addressing psychological, social, emotional and spiritual needs associated with the disease process. The goal is a more comfortable existence without prolonging the dying process or aggressively sustaining a quality of life that would be unacceptable to the patient. Comfort care may include invasive interventions (such as transfusions, surgery, radiation) for pain or other symptoms. More often, comfort care uses less invasive methods to support the patient’s physical and emotional well-being, such as medication, physical therapy and relaxation techniques, counseling and spiritual guidance.
Principles on which these recommendations are based
Medical science provides physicians with the means of improving the health and prolonging the lives of most patients. However, interventions are sometimes applied in circumstances or in ways that may not serve the goals of both patients and physicians.

The decision to use medical interventions relies not only on medical science but also on patients' perspectives on quality of life, risk-taking and what constitutes beneficial care. Goals and values of patients and their families are fundamental to decisions to accept or refuse medical treatment. Healthcare providers also have goals, values and professional standards that guide their recommendation of treatment options. Central to ECHO is the belief that medical treatment decisions should involve a mutually respectful partnership among the patient, family and healthcare team.

The principles underlying the ECHO recommendations

Patient autonomy
The right of self-determination includes the right of competent adults to choose among appropriate treatment alternatives and to refuse any treatment offered. To exercise this right in a meaningful way, patients/surrogates must have the necessary information and the opportunity to make an informed decision.

Avoiding harm
Aggressive, cure-oriented treatment may constitute a harm, unless the medical benefit to the patient is apparent, is congruent with the patient's goals and outweighs the burden to the patient. When cure is no longer possible and either death is imminent or a profoundly diminished condition unacceptable to the patient is expected, healthcare professionals should not recommend procedures that increase patients' pain and suffering.

Benefiting the patient
Providing for humane care that respects the dignity of the patient requires far more than the avoidance of harm. The treatment provided by the healthcare team for those terminally or profoundly, irreversibly ill must be purposefully and conscientiously aimed at meeting the patient's physical, psychological, social, spiritual and emotional needs in an environment of caring and support.

Medical integrity and the goals of medicine
The goal of treatment should be improvement of the patient's prognosis, comfort, well-being, or general state of health, or maintenance at a level of functioning that constitutes a quality of life satisfactory to the patient. There are limits to what medicine can achieve. The physician's recommendation of interventions that have little likelihood of meaningful benefit to the patient may create unrealistic expectations about medicine and the patient's prognosis. It may deprive the patient of peaceful, humane support at the end of life. Nonmedical goals, such as meeting the family's emotional needs, must be recognized and addressed with compassion, while balanced with the principles of responsible and effective clinical practice.

Wise use of societal and personal resources
Medical interventions can be extraordinarily expensive. If treatment can neither maintain nor improve health, nor restore function, it may be both fruitless and wasteful. Though the cost of treatment should not be the primary reason for precluding a treatment option, healthcare providers and consumers have a duty to be wise stewards of communal resources. Likewise, all must be aware of the financial burdens often borne by patients and families.
Goals and Strategies for Acute Care Facilities

GOAL 1:
Develop treatment options that are responsive to the needs of dying or irreversibly ill patients and their families.

Strategies
1.1 Incorporate a statement of principles regarding the institution’s role in the care of terminally or profoundly, irreversibly ill patients.
1.2 Develop and implement comfort care protocols, including procedures for transitioning patients and families from cure-oriented to comfort care and timely referral to hospice.
1.3 Provide training for physicians and multidisciplinary staff in the provision of comfort care in all hospital settings.

GOAL 2:
Identify patients at risk of inappropriate or unwanted medical treatment.

Strategies
2.1 Adopt and implement Indicators for Offering Comfort Care (page 5).
2.2 Establish and maintain an ongoing process for reviewing ICU patients for appropriate treatment: cure-oriented or comfort care.
2.3 Include in quality-of-care activities evaluation mechanisms for the appropriate use of comfort care protocols, adherence to advance directives, etc.
2.4 Sponsor educational programs for health professionals on the identification of at-risk patients and the availability and use of hospice and other community services.

GOAL 3:
Improve communication among patients, families, physicians, other healthcare team members and healthcare settings in order to foster informed, timely and mutually satisfactory treatment decisions.

Strategies
3.1 Define expectations for communication about end-of-life care.
3.2 Train healthcare personnel in communication about end-of-life care, which takes into account cultural and religious differences.
3.3 Initiate institutional changes for eliciting, documenting and sharing relevant information among patient/surrogate, primary care physician, specialists, other healthcare professionals and between acute and long-term-care settings.
3.4 Provide emotional support/grief counseling for patients, families and the healthcare team confronting end-of-life treatment decisions.
3.5 Develop materials and training for patients/surrogates and community members concerning their rights and responsibilities in communication about end-of-life issues.

(See Improving Communication about Treatment Decisions, page 8)
GOAL 4:
Assure that the patient/surrogate is the primary decision-maker in choosing among appropriate treatment options.

Strategies
4.1 Evaluate current presence of, and compliance with, advance directives in patient charts; establish objectives for improvement.
4.2 Educate patients/surrogates and healthcare professionals about institutional policies (including the use of the Bioethics Committee) that address ethical concerns about treatment decisions.
4.3 Develop and sponsor community education programs to increase public awareness of, and participation in, advance planning for end-of-life decisions.

GOAL 5:
Support effective processes for preventing and resolving conflicts regarding treatment decisions that respect patient values and the professional integrity of healthcare providers.

Strategies
5.1 Educate healthcare professionals and consumers about common areas of miscommunication or misunderstanding concerning end-of-life treatment decisions.
5.2 Improve the knowledge, skills, visibility and accessibility of the institution's Bioethics Committee.
5.3 Improve physicians' understanding of current legal and ethical rights and obligations in providing and withholding life-prolonging treatment.
5.4 Explore an open and fair process that considers and resolves physicians' concerns about demands for medically inappropriate care.
Indicators for Offering Comfort Care

**Adult patients or their surrogates**
If cure-oriented treatment is no longer medically appropriate or desired by the patient/surrogate, then the principle of beneficence obligates the healthcare provider to make comfort care available.

If the patient has not explicitly indicated—verbally, in writing or through a surrogate—a desire to forego cure-oriented treatment, comfort care should nevertheless be considered and discussed with the patient/surrogate if:

- The patient is terminally ill.
- A profoundly diminished quality of life is imminent or has been established as irreversible.

**In the following circumstances, comfort care must be offered as an option:**
1. Persistent vegetative state
2. Minimal cognitive function (absence of self-awareness or awareness of others) that is irreversible
3. The burdens to the patient of cure-oriented treatment are greater than the medical benefit to the patient
4. Irreversible and irreparable (multi)organ failure
5. Imminent demise

**Nonviable or irreversibly ill newborns**
Advances in medical technology have improved the outcomes of many infants born prematurely or with complex medical conditions. It is now possible to keep devastated newborns alive for long periods of time. An unintended consequence of such treatment is a prolonged dying process for some newborns or the survival of some infants with severely debilitating conditions. Medical treatment of infants should be based on consideration of the benefits and burdens of life-sustaining medical treatment and determination of what is in the infant's best interest. Reaching these decisions through collaboration between the parents and the healthcare team is the goal.

**Comfort care may be the most appropriate option to offer parents in a variety of situations, such as:**
1. Conditions for which life expectancy is severely limited even with aggressive therapy. Current examples include but are not limited to:
   - Profound perinatal asphyxia
   - Prematurity less than 23 weeks and under 500 grams
   - Severe multiple congenital anomalies
2. Conditions for which cognition may reasonably be expected to be absent or profoundly limited. Current examples include but are not limited to:
   - Anencecephaly
   - Trisomy 18
   - Trisomy 13
3. Conditions for which morbidity is so great and care is so extremely burdensome to the patient that quality of life is severely impaired. Current examples include but are not limited to:
   - Osteogenesis imperfecta type 2
   - Multisystem organ failure
Roles of Other Key Healthcare Providers

Appropriate end-of-life care is an inter-institutional, interdisciplinary obligation. The goals stated in this document are relevant not only to acute care facilities but also to long-term-care settings, physicians groups, health plans, professional associations, regulatory agencies and others. The interdependence of healthcare providers and settings is such that success in achieving appropriate care for dying patients requires a coordinated and cooperative approach.

The ECHO project urges other providers to also commit to ECHO goals and strategies that are relevant to their setting or constituency.

Physicians/medical groups

Physicians are increasingly expected to do more for patients in less time, making discussions about end-of-life care more difficult. Physicians are, however, the authorities on realistic and feasible medical treatment options and should not abdicate their role in discussing these issues with patients/surrogates.

Physicians should be responsible for the following:

1. Identify patients most at risk of unwanted or inappropriate medical treatment (e.g., residents in long-term-care settings; those with progressive, incurable conditions) and initiate discussions before a medical crisis occurs.

2. Provide patients/surrogates with clear, understandable information regarding condition, prognosis, treatment options, risks/benefits and potential outcomes.

3. Be familiar with the principles and application of comfort care interventions.

4. Improve their communication skills in discussing end-of-life decisions with patients/surrogates.

5. Involve other members of the healthcare team—nurses, social workers, clergy—to assist with patient/surrogate communication.

6. Provide advance directive materials for patients (e.g., in waiting rooms and other outpatient settings) and include advance directive inquiries on information sheets for new patients.

7. Assess the decision-making capacity of patients.

8. Assure that patients’ completed advance directives forms and/or chart notes about patient wishes become part of inpatient medical records.

9. Stay informed on institutional policies, procedures, legal and ethical issues related to end-of-life decisions; consult with the Bioethics Committee to seek advice, as needed.

Long-term-care settings

Existing policies for skilled nursing facilities (SNFs) directly affect when and why terminally or irreversibly ill patients are transferred to and from acute care facilities. These policies—determined by regulatory, financial and logistical circumstances—may impede the provision of comfort care interventions within the SNF setting.

Most of the goals and strategies listed previously also apply in long-term-care settings, especially skilled nursing facilities. To assure that these recommendations can benefit SNF patients and their families, the ECHO project recommends that a task force be convened of local and state leaders from the long-term-care industry. This task force should explore existing barriers and propose changes that will facilitate the provision of comfort care in all long-term-care settings and improve communication and coordination between SNFs and other providers.
Health plans and payers
As healthcare systems evolve, there are opportunities to develop new approaches to end-of-life care. Health plans and payers must be responsive to the need to support and strengthen appropriate and humane end-of-life care both within and outside the hospital setting. Consistent with health plans' role in providing member education, information and preventive services, plans should also assume greater responsibility for educating healthcare professionals and consumers about end-of-life care.

Health plans should be responsible for the following:

1. Sponsor physician education seminars on such subjects as:
   - Physician-patient/surrogate communication skills concerning end-of-life decisions.
   - Sensitivity to cultural and religious differences.
   - Comfort care plans including pain management.
   - Ethical and legal standards concerning termination of treatment.

2. Develop mechanisms that encourage physicians to conduct planned and purposeful discussions with high-risk patients (those with progressively debilitating or terminal illnesses) about their values and goals related to end-of-life treatment.

3. Work with community-based organizations in planning and conducting consumer education programs designed to educate the public about advance directives and encourage consumer responsibility for communicating personal end-of-life values.

4. Provide educational tools—e.g., videos, informational booklets, discussion guides—related to end-of-life decisions for use by health plan members, physicians, nurses, clergy and community organizations.

5. Provide advance directive documents for any health plan member upon request.

6. Sponsor educational programs specifically for public and private guardians or conservators acting as medical surrogates.

7. Review health plan benefits to assure consistency in support of the provision of comfort care interventions.
Improving Communication About Treatment Decisions

Improving communication is key to achieving all five goals. In considering the strategies for Goal 3, the ECHO project has identified important elements that could be incorporated into policies or procedures.

**Adult patients or their surrogates**

Identifying and responding to patients who are at risk of non-beneficial or unwanted medical treatment are the responsibilities of the patient's primary physician in conjunction with other healthcare professionals: specialists, nurses, social workers and clergy. A multi-disciplinary approach is recommended. Communication and decision-making among patients, families and providers can be improved by adoption of the following:

A. **Elicit and share relevant information**

Under the direction of the primary physician (or, when appropriate, the midlevel practitioner), the team has the responsibility to elicit, document and share with other team members relevant information about the patient’s values and end-of-life preferences. Others involved with the care of the patient also have the responsibility to share relevant information with team members.

Ideally, planning for future care with the patient/surrogate should take place over time, on a regular basis and as needed by changes in the patient’s clinical condition. There may be many opportunities and methodologies for gathering and sharing information.

The healthcare team should be responsible for the following:

1. Provide clear and timely information to the patient/surrogate regarding diagnosis, prognosis, expected level of functioning and extent of medical and social needs required by the patient.
2. Seek to understand the patient/surrogate’s goals and expectations.
3. Present treatment options that are congruent with the patient’s goals.
4. If cure-oriented treatment cannot be recommended, explain to patient/surrogate the medical reasons for that judgment.
5. Be aware of, and sensitive to, cultural, religious and social differences that may influence the roles which the patient and family play in medical decision-making.
6. To the extent possible, provide patient/surrogate the time needed for making or accepting treatment decisions.
7. Follow established protocols for assessing patient’s decision-making capacity.
8. Establish timely and effective mechanisms for receiving and sending advance directives and patient preference information between healthcare facilities and agencies involved in the patient’s care.
9. Document clearly the communication held with patient/surrogate about these issues.

The patient/surrogate is always central to decision-making. As such, he or she must be as informed as possible regarding issues related to personal treatment choices and actively participate in communication and decision-making.

Patients/surrogates should be responsible for the following:

1. Discuss end-of-life treatment choices with family members, significant others, clergy and healthcare providers within the context of patients’ cultural or religious beliefs.
2. Be receptive and available to the healthcare team for discussing patient’s condition, needs, goals, expectations and treatment options.
3. Be proactive in soliciting the involvement of the primary physician in discussing end-of-life treatment options.

4. Alert providers if an advance directive has been completed and provide a copy of the document for inclusion in the patient’s medical record.

5. Consider designating one family member to be the main contact with the healthcare team if communication between the family and team is complex.

B. Have sufficient understanding of ethical, legal and institutional policies

Healthcare professionals and patients/surrogates should know, for example, that:

1. Treatment choices may include the option not to treat.

2. “Not treating” is not the same as doing nothing; comfort care protocols should be described as a treatment option.

3. The plan of action for the patient can be changed as circumstances change; the option to stop treatment may become as important as the option to start treatment.

4. There are institutional processes for clarifying ethical or legal uncertainties and to help resolve conflicts between the patient, surrogate and healthcare team.

C. Assure appropriate decisions about terminating life-support in the absence of a competent patient or surrogate.

When the patient is not competent to make his or her own decisions and there are no family members or surrogates who can speak on the patient’s behalf, then any decision to terminate cure-oriented management should be reviewed (in advance, when possible) with the institution’s bioethics committee or other designated team.

Patients in long-term-care settings can be particularly vulnerable to the inappropriate provision (or withholding) of cure-oriented medical treatment, and a system for patient review should be in place.

Parents of a nonviable or irreversibly ill newborn

Communication with parents is a critically important responsibility of all members of the healthcare team. In order to achieve maximum effectiveness, communication needs to be ongoing, planned and purposeful in nature. The following principles should be incorporated in the policies and procedures for each labor and delivery department, newborn nursery and neonatal intensive care unit:

A. Elicit and share relevant information

The healthcare team should be responsible for the following:

1. Make every effort to reach agreement among the healthcare team before presenting and recommending treatment options to the parents.

2. Keep parents apprised of all aspects of care and treatment of their infant, including treatment options, their consequences and the types of immediate and long-term care needs.

3. As needed, offer assistance to help them understand what the long-term consequences may be for an infant with a devastating condition.

4. Elicit from parents their willingness and ability to care for an infant who will need complex support at home.

5. To the extent possible, provide parents the time needed for making or accepting treatment decisions.

6. If cure-oriented treatment cannot be recommended, physicians should explain to parents the medical reasons for that judgment.

7. Provide emotional support to families and assure parents that their child has value, regardless of decisions made or treatment outcome.
B. Make and reconsider treatment decisions

Healthcare team responsibilities:
1. It is generally better to resuscitate and later forego support if that becomes appropriate, rather than to not provide support initially in situations where:
   - The parents are ambivalent or there is disagreement between the parents.
   - The physician is uncertain about viability.
   - Sufficient time before delivery did not allow a discussion to develop between the parents and physician.
2. Make recommendations only for options that are consistent with sound medical practice.
3. When cure-oriented intervention has been agreed upon, the decision should be revisited:
   - If the infant fails to show the expected response.
   - Whenever there is a significant change in the infant’s health status.
   - When a parent or healthcare professional asks for re-evaluation.
4. In the face of new information, everyone should be prepared to alter decisions.
5. Where further discussion is necessary, it is important to continue supporting the infant until areas of controversy can be resolved.
6. When comfort care is offered, it is offered as respectful and compassionate treatment.

The parents are always central in the decision-making process. For parents to make informed decisions, it is important that they be as active as possible in discussions related to treatment choices.

Parents responsibilities:
1. Be available to discuss issues related to the infant’s condition, treatment options, their consequences and the types of immediate and long-term care.
2. Be timely in responding to the informational needs of members of the healthcare team.
3. Identify those family members who are the key decision-makers for the infant.
4. Seek assistance from members of the healthcare team when more information is needed.
5. Seek information from community resources to fully understand the support required for a severely impaired child.
6. Be prepared to alter decisions in the face of new information.
Appendices

Appendix A
Overview of the ECHO Project

Appendix B
ECHO Committees

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Public Dialogue Groups
ECHO Moderators
APPENDIX A


Sponsoring organization
Sacramento Healthcare Decisions (SHD) is a nonprofit, nonpartisan organization committed to involving the public in healthcare policy and practice issues. SHD facilitates communication among healthcare consumers, providers and policymakers. Additional information about SHD or ECHO is available by calling (916) 484-2485.

Project funding
ECHO is funded through a grant from Sierra Health Foundation. Additional support has been provided by Mercy Healthcare Sacramento, Kaiser Permanente Medical Care Program, Sutter Community Hospitals, the California Association of Catholic Hospitals and the Sacramento-El Dorado Medical Society Alliance.

ECHO’s collaborative process
Based on SHD’s mission that the public’s voice must be included in healthcare changes, identifying and incorporating public values was a critical element to this process. Therefore, ECHO emphasized a two-pronged approach: a community-based public dialogue and a multidisciplinary, inter-organizational clinical dialogue. Under the direction of ECHO’s Steering Committee, several components were developed for the dialogues. The final ECHO document merges public and provider perspectives.

Public dialogue
- Ninety-two public discussion groups were held in Sacramento, Yolo, Placer and El Dorado Counties. Led by 52 trained moderators, these two-hour structured, interactive discussions provided 972 residents with the opportunity to discuss the values, priorities and trade-offs they feel are most critical when decisions are made about appropriate end-of-life medical treatment.
- To identify specific aspects of communication and decision-making that arise, a focus group was held with families who had recently experienced difficult end-of-life decisions.
- A 1,022 person random telephone survey was conducted addressing these and related issues, augmenting the discussion groups’ qualitative results with quantitative data.

Clinical dialogue
- Three separate, multihospital clinical committees—Adult Intensive Care, Neonatal Intensive Care and Long-Term Care—met for about a year to develop their recommendations.
- A Conflict Resolution Committee was formed to look specifically at the issue of providers’ concerns about demands for medically inappropriate care.
- SHD distributed a Physician Survey on End-of-Life Ethics to nine hospitals in the region. With more than 1,500 physicians participating, this survey is a tool to identify educational needs and to encourage changes in practice.
Communicating and reviewing the results

- A half-day forum, *Seeking Common Ground: Medical Treatment at the Margins of Life*, was held in June 1996, bringing together more than 300 healthcare professionals, policymakers, and community members to hear and comment on the results of ECHO's dialogues.
- A draft version of the ECHO report was reviewed by local bioethics committees; more than 600 copies were distributed on request to local residents and interested healthcare leaders in California and 18 other states.
- The draft report was reviewed and endorsed by the Board of Directors of the Sacramento-El Dorado Medical Society.
- Seventeen community groups were convened to review and discuss the draft document.
- An Education Committee began identifying physician, staff, patient and community needs and opportunities.
- The print and broadcast media reported on ECHO in detail, with substantive coverage in *The Sacramento Bee*, *The Business Journal, California Medicine* and other local and state publications.

### Project Timeline

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APPENDIX B
ECHO Committees

Steering Committee

Fran Alberghini, MSW
Chief, Sac. County Senior & Adult Services
Clifford Anderson, PhD
Professor of Philosophy, CSUS
Vicki Bailey
Hospital chaplain/counselor
Janet Carter
California Association of Catholic Hospitals
Monique Cesna, CCRN
Mercy San Juan Hospital
Byron Chell, JD
California Medical Assistance Commission
Lori Dangberg
Mercy Healthcare Sacramento
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Donald Kohrin, MD
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Elizabeth Mackenzie
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MJ Nealon, RN, MPH, MSN
Woodland Healthcare, Bioethics Comm. Co-Chair
Ellen Robinson-Haynes, MA
UC Davis Violence Prevention Research Program
Michelle Schwartz, RN, MPH, MPP
Berkeley Bioethics Associates
Howard Slyter, MD
Kaiser Sacramento, Bioethics Comm. Chair
Bruce Spurlock, MD
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Medical Director of Clinics, Sac. County
Michael Tscheu, LCSW
Director, Sutter Hospice
Carol Zerbo
Community member

Public Dialogue Committee

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Moroni Leash, LCSW
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Diane McCann, EdD
UC Davis Medical Center (ret.)
Ellen Robinson-Haynes, MA
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Michelle Schwartz, RN, MPH, MPP
Berkeley Bioethics Associates
Carol Zerbo
Community member

Staffing
As Project Director, Marjorie Ginsburg participated in
and provided staffing for all ECHO committees. Anita
Cativin, MSN, FNP assisted with the Neonatology
Committee. SHD staff members Kathy Glasmire and
Devara Berger, MPA, assisted with other committee
work.
Adult Intensive Care Committee

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UC Davis Medical Center  
Monique Cesna, CCRN  
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Kathy Chetley, RN  
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Darshan Sonik, MD  
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MedClinic
Marie Nitz, RN
Gero-Psych Unit, MedClinic
Cheryl Phillips-Harris, MD
Sutter Community Hospitals
Gay Raney, RN
Kaiser So. Sacramento
Karen Walton, LCSW
Corporate Consultant, Eskaton
Carol Zerbo
Community member

Conflict Resolution Committee

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Calif Assn of Health Facilities
Byron Chell, JD
California Medical Assistance Commission
Denise Crum, RNC
Quality & Health Consultant, Eskaton
Mike Dickey
Community member
Susan A. Fossum, PhD
Psychologist
Karen Guthrie, JD
Marshall Hospital Bioethics Comm.

Sr. Marilee Howard, PhD
Sisters of Mercy, Auburn
Charity Kenyon, JD
Diepenbrock, Wulff, Plant & Hannegan
Judge Barry Loncke
Sacramento Municipal and Superior Court
Mary Parks, JD
Medical-Legal Affairs, Kaiser Permanente
Robert Quadro, MD
Medical Director, Mercy Hospice
Howard Slyter, MD
Kaiser Sacramento
Andrew Wertz, MD
Sutter Memorial Hospital

Education Committee

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Linda Anderson, RN
Sutter General Hospital
Nancy Asmus, RN
Marshall Hospital
Deborah Brady, RN
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Margaret Clausen, CAE
Director, Calif. State Hospice Association
Sue Clement, RN
Sutter General Hospital
Horti Davis, RN
Sutter Roseville
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Deborah Ogrod, RN, MSN
UC Davis Medical Center
Joel Porter, RT
Marshall Hospital
Gay Raney, RN
Kaiser So. Sacramento
Jean Steel
Kaiser Davis and Sacramento
## APPENDIX C

### Public Dialogue Groups

**ECHO Discussion Groups**
*(October 1995 - March 1996)*

Total number of groups held: 92  
Total number of participants: 972

Demographics of participants *(not every participant completed the demographic form)*

<table>
<thead>
<tr>
<th>Gender (N=916)</th>
<th>Residence (N=920)</th>
<th>Ethnicity (N=913)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>El Dorado 49</td>
<td>Afr. Amer. 52 (6%)</td>
</tr>
<tr>
<td>Female</td>
<td>Placer 125</td>
<td>Hispanic 35 (4%)</td>
</tr>
<tr>
<td>Age (N=912)</td>
<td>Sacramento 553</td>
<td>Asian 52 (6%)</td>
</tr>
<tr>
<td>18-34</td>
<td>Yolo 147</td>
<td>Nat. Amer. 22 (2%)</td>
</tr>
<tr>
<td>35-64</td>
<td>Other 46</td>
<td>White 740 (81%)</td>
</tr>
<tr>
<td>65+</td>
<td></td>
<td>Other 14 (2%)</td>
</tr>
</tbody>
</table>

### List of group discussions

**Church/religious groups:** 58
- Atonement Lutheran Church, Rosemont (2)
- The Bellry-UC Davis campus ministry
- Bethany Presbyterian Church (2)
- Bethel Lutheran Church, Roseville
- Calvary Lutheran Church, Rio Linda
- Community Lutheran Church, West Sac.
- Cordova United Presbyterian Church (2)
- Davis Community Church (3)
- Davis Lutheran Church
- El Dorado County Federated Church
- ELCA Clergy
- Faith Evangelical Presbyterian Group, Folsom
- Faith Lutheran Church, Meadow Vista (2)
- First Cong. United Church of Christ, Auburn
- First English Lutheran Church, Oak Park
- Good Shepherd Lutheran Church
- Grace Lutheran Church, Rancho Cordova (2)
- Holy Family Church Women’s Council (2)
- Loomis Methodist Church
- Lutheran Church of the Cross
- Missouri Synod Lutheran Pastors (2)
- Progressive Area Lutheran Singles
- So. Sacramento Christian Center
- St. Andrews AME
- St. John’s Lutheran Church
- Trinity Cathedral
- Trinity Presbyterian Church, West Sac. (2)
- UCD Chaplaincy Services

**Boards/professional associations:** 15
- Adult and Aging Commission (2)
- California Retired Teachers Assn. (5)
- Leadership Sacramento (3)
- Mercy Health Ministries members (2)
- Public Health Advisory Committee
- UCDMC Community Advisory Board

**Workplace/volunteers:** 13
- Asian agencies staff (2)
- Sac. Co. Dept. of Health and Human Svcs. staff
- Sac. Co. Dept. of Medical Systems staff
- CSUS Psychological Services staff
- El Dorado County Health Dept. staff
- Kaiser Davis volunteers
- Kaiser South Sacramento volunteers
- Mercy Folsom Hospital Auxiliary (2)
- Resources for Independent Living staff
- Sutter Adolescent Family Life Prog. staff
- Sierra Health Foundation staff

**Education related:** 12
- CSUS Bioethics class (5)
- CSUS MSW Policy class (4)
- Golden Gate University graduate students
- Sierra College Human Dev. classes (4)

**Private homes:** 12

**Other:** 2
- Alzheimers Support Group, Placerville
- Filipino community group
ECHO Moderators

Fran Alberghini  
Sac. Co. Senior & Adult Services

Mary Baker  
Private home health RN

Phyllis Bolt  
Retired RN, Davis

Louis Bronson  
Retired Social Work professor

Maria Carrillo-Shore  
Former community clinic administrator

Jan Carter  
California Assn. of Catholic Hospitals

Carole Ching  
Asian Resources

Sharron Clark  
Private home health RN

Gail Conners  
Volunteer Services Director, Sutter

Nancy Culifer  
Mercy Folsom RN

Lori Dangberg  
Mercy Healthcare Sacramento

Susan DeMarois  
California Assoc. of Homes & Services for the Aging

Susan Fossum  
UC Davis Medical Center RN

Donna Fulmer  
Marshall Hospital RN

Michael Gaddini  
Mercy Folsom MD

Kent Gary  
Transit Manager, City of Folsom

Bonnie Gieschen  
Kaiser So. Sacramento MD

Holly Hindelang  
Mercy Folsom RN

Lisa Hoffman  
Sutter clinical social worker

Judith Hwang  
UC Davis Medical Center MD

Gail Jackson  
Marshall Hospital RN

Paul Janke  
Inland Area Coordinator, Lutheran Social Services

Lori Jarvis-Steinwelt  
Sierra Health Foundation

Corrine Joe  
Sutter hospital administrator

Henry Kano  
Woodland Healthcare MD

Sunita Kapoor  
Kaiser Sacramento RN

Diane Keys  
Community Services Planning Council

Betty Kirby  
Roseville Hospital RN

Mary Anne Kirchner  
Volunteer supervisor, Mercy Hospice

Yvonne J. Kochanowski  
Business/healthcare consultant, Placerville

Marsha M. Lang  
Attorney, consultant

Moroni Leash  
Kaiser Sacramento clinical social worker

Sally Liedholm  
Public Guardian, El Dorado County

Bill Mason  
Retired hospital administrator, Sutter Health

Diane McCann  
Health educator

Althea Moynihan  
Planning consultant, RN

MJ Nealon  
Nursing instructor, Woodland

Judith B. Osen  
Community volunteer, Roseville Hospice

Steven M. Paul  
Kaiser Sacramento manager

Karyn Piche  
Access Health

Stephen Price  
Dialysis RN

Gay Raney  
Kaiser Souh Sacramento RN

Susan Roberts  
Sutter RN

Adele J. Rothermel  
Yolo County Dept. of Social Services

Star Rudge  
Omni Health Care RN

Henry Sepulveda  
Public administrator, attorney

Howard Slyter  
Kaiser Sacramento MD

Marsha Vacca  
California Healthcare Association

Heidi Weiland  
El Dorado County mediator

Hach Yasumura  
Sac. Co. Department of Social Services

Andy Zerbo  
Community member, Rochlin

Carol Zerbo  
Community member, Rochlin