

**The Reality—**

**RWJ Foundation Project on  
Improving End of Life**

Oakland, California

November, 2001

# ***Institute of Medicine***

## ***Dimensions and Deficiencies***

- I. Too many people suffer needlessly at the end of life, both from errors of omission and from errors in commission.**
  
- II. Legal, organizational, and economic obstacles conspire to obstruct reliably excellent care at the end of life.**

***Approaching Death, Nat'l Academy Press, 1997***

# ***Institute of Medicine***

## ***Dimensions and Deficiencies***

- III. The education and training of physicians and other health care professionals fail to provide them the attitudes, knowledge, and skills required to care well for the dying patient.**
  
- IV. Current knowledge and understanding are insufficient to guide and support the consistent practice of evidence-based medicine at the end of life.**

# Health Care Facts in USA

- ✱ **American people are not happy about how their loved ones or friends die –**
  - ✱ **lack of a “good death”**
- ✱ **Highly inadequate use of analgesics in the EOL**
- ✱ **Medical expense is staggeringly high, leading to impoverished families**
- ✱ **Unacceptable, statistically significant, risk factor associated with minorities, the elder, and the poor**

# Health Care Predictions in USA

- ✦ **At any scenario predicted, the uninsured will not disappear but grow (30 to 65 million) as will the underinsured.**
- ✦ **40 millions are now either ill or disabled, which is expected to increase in the next decades**
- ✦ **The elderly population is also rapidly growing**
- ✦ **1.6 million people live in nursing homes today; in the next 30 year, the number will rise by 5.3 million**

# **Serious Issue 1**

**“In recent surveys, support for legalizing physician-assisted suicide is running between 60-70%. This is dramatic evidence of peoples’ anger, and fear. The public is fed up and wants to take back responsibility for their own lives.”**

**“In the circumstances in which people suffer with their illness-related disability, their symptoms, and sense of being a burden to society, the choice of suicide may be entirely rationale, but it is all the more tragic...”**

**Ira R. Byock, 2001**

# Serious Issue 2

**“It’s pretty clear that at least some of the medicalized misery that dying has become is self-inflicted. As Pogo once observed, ‘*We have met the enemy and he is us.*’ In truth, a collective denial of dying, death and advancing morbidity is the constant that runs through the confused and conflicted state of affairs that typifies the American way of death.”**

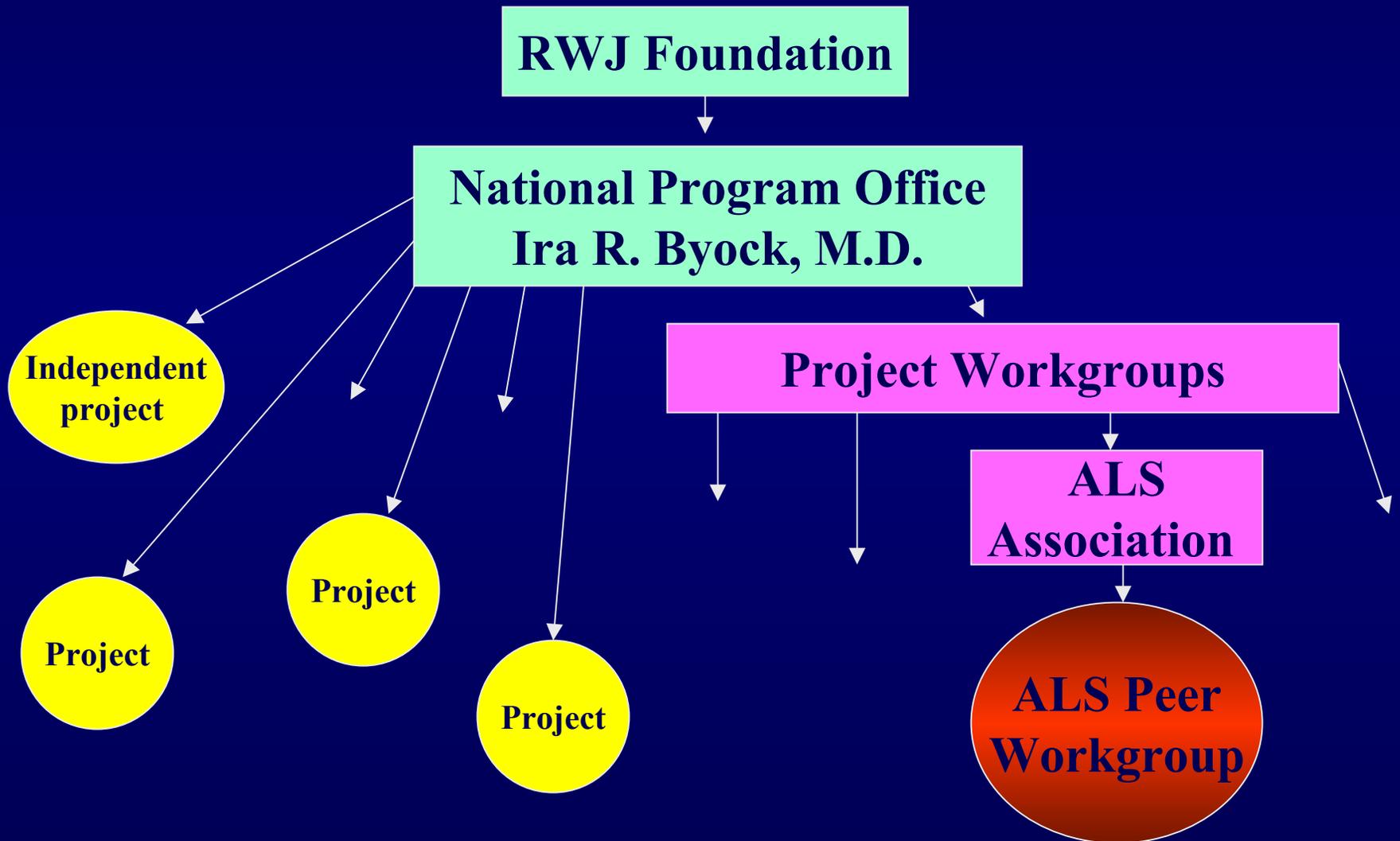
**Ira R. Byock, 2000**

**Palliative Care or End-of-Life (EOL) Care is an Important Alternative**

# End of Life – ALS Database

- ✦ Of 373 patients who died, 56% died at home, 19% in hospital, 7% in hospice
- ✦ 47% who died at home used hospice facilities
- ✦ 89% recorded as dying peacefully
- ✦ 66% used medications to control pain, distress
- ✦ 37% received oxygen in terminal period
- ✦ Advance directives in place in 90% of cases; followed 97% of the time

# Robert Wood Johnson Initiative



# ALS Peer Workgroup

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Rup Tandan, MD, Burlington, VT

Andrea Versnyi, CSW, NYC

# ALS Peer Workgroup Mission

- 1. Development of an accurate description of the state of the field**
- 2. Creation of a road map to improve EOL**
- 3. Dissemination of Workgroup results**
- 4. Going beyond dissemination**

# Dissemination of ALS Workgroup Recommendations



# Work in Progress

- ✦ **Inauguration Meeting at Airlie House, 5/1999**
  - ✦ Overall goals, plan, process, and subcommittees
- ✦ **Conference calls among the subcommittees**
- ✦ **Exchange the information via RWJ website**
- ✦ **Midterm meeting at Aarhus, 11/2000**
- ✦ **Subcommittee meetings in the summer**
- ✦ **Wrap-up meeting at Scottsdale, 11/2001**

# **Palliative Care**

## **End-of-Life Care**

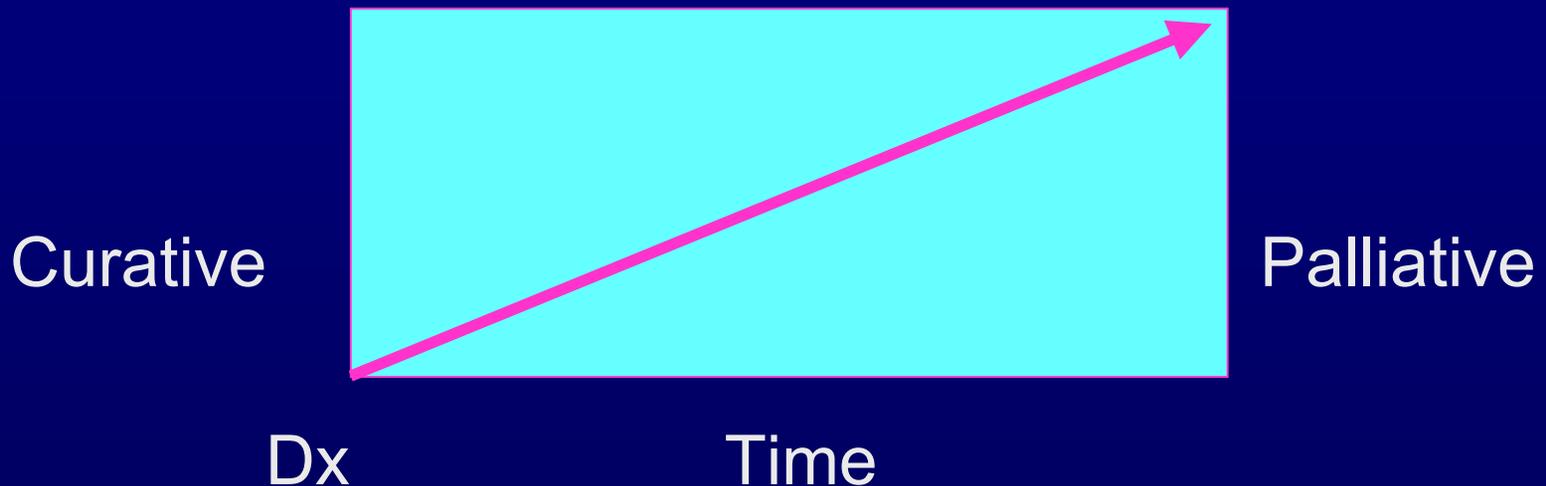
# Palliative Care –

## *WHO Definition*

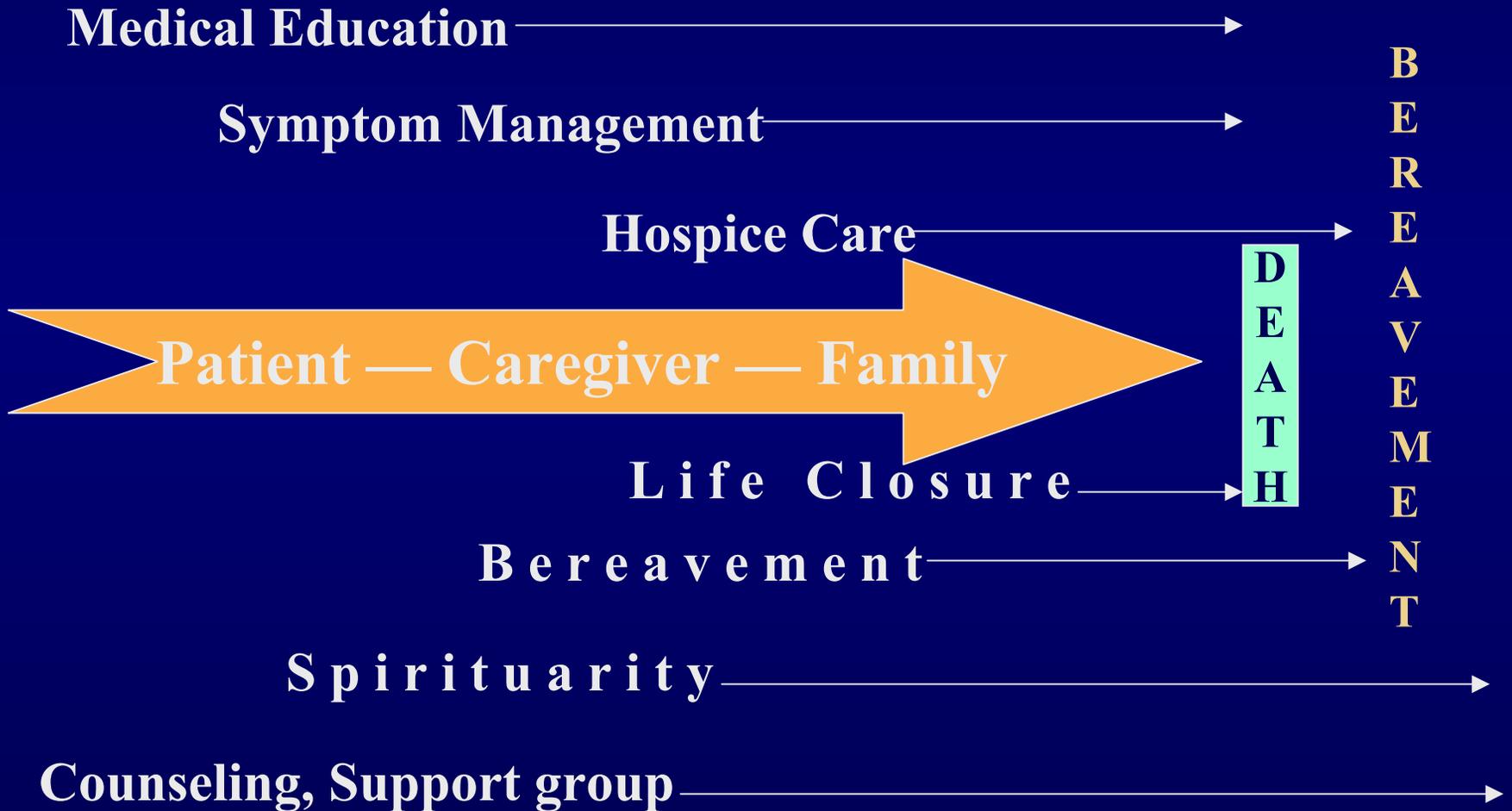
**“The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families.... palliative care...affirms life and regards dying as a normal process...”**

# When does the end of life begin?

At the time of the diagnosis of ALS made? *Or...*  
Sometime later, but when?



# EOL and Palliative Care



# The Operational Definition of EOL in ALS: 6 “Triggers”

- 1. The patient or family asks – or “opens the door” for end-of-life information and/or interventions (elicited or spontaneous, verbal or non-verbal), or**
- 2. Severe psychological and/or social or spiritual distress or suffering, or**
- 3. Pain requiring opiates, or**
- 4. Dysphagia requiring feeding tube, or**
- 5. Dyspnea or symptoms of hypoventilation, forced vital capacity at 50% or less, or**
- 6. Loss of function in two body regions**

# Clinicians Must Review Their Own Experience and Attitude

- ✦ **Clinicians first must come to terms with their own deaths.**
- ✦ **Clinicians' own attitudes about dying and choices they may or they may not make for themselves.**

# End-of Life Subcommittees

- ★ **Ethics, Communication, and Decision Making**  
*Wendy Johnston, MD, Chair*
- ★ **Psychosocial Care**  
*Mark Bromberg, MD, Chair*
- ★ **Access of Care, Cost of Care, and Knowledge/  
Education**  
*Rup Tandan, MD, Chair*
- ★ **Symptom Management**  
*All members*

# Ethics, Communication, and Decision Making

## Physicians

- ✦ Lack of familiarity of how to discuss difficult issues:
  - ✦ Dx of ALS, need for assistive devices, end-of-life discussions
- ✦ Too much too late is a consistent issue for ALS care
- ✦ Reluctant to treat the end of life patient as they are “futile”
- ✦ Lack of knowledge on use of pain-control medications and the issue of withdrawing life-sustaining treatment
- ✦ Lack of knowledge about ALS in other specialties:
  - ✦ PEG, NIPPV, Trach, Hospice care, etc.

# Ethics, Communication, and Decision Making – *Recommendations*

## ☀ Practice

- ☀ Improve physician's communication skills with patients/caregivers
- ☀ Improve physician's comfort and familiarity with end-of-life issues
- ☀ Promote a patient bill of rights
- ☀ Patients need access to good "*standards of care*"

## ☀ Clinical Research

- ☀ Analysis of timing, quality, quantity, and nature of the communication (between physicians and patients) and outcomes

## ☀ Policy

- ☀ Improve the educational program at all levels

# Psychosocial Care

- ✦ Bereavement
- ✦ Spirituality
- ✦ Quality of Life
- ✦ Family Caregivers
- ✦ Overall Psychosocial Intervention
  - ✦ Hope while dying
  - ✦ Coping and counseling
  - ✦ Sexuality & intimacy
  - ✦ Needs of children
  - ✦ Dying & life closure
  - ✦ Ethnic and cultural difference

# Bereavement

- ✦ Bereavement is a process that begins when something is lost or someone dies; grief is the feeling of sadness associated with the loss; and mourning is the expression of sorrow and grief.
- ✦ Uniqueness of bereavement in patients with ALS (progressive with loss of function)
- ✦ Uniqueness of bereavement in caregivers
  - ✦ Bereavement vs. relief and guilt
- ✦ Research: basic data needs to be accumulated in patients and their caregivers

# Spirituality

## ✦ Present Status

- ✦ Spiritual needs are still largely neglected even in the context of end-of-life care

## ✦ Practice Recommendations

- ✦ Incorporate spiritual care as an integral component of palliative care for the patients and their families by the multidisciplinary ALS team
- ✦ Professional involved in the care of patients with ALS should have spiritual care education

# Spirituality

## ✦ Research Recommendations

- ✦ Improve the evidence base for spiritual care interventions

## ✦ Policy Recommendations

- ✦ Focus efforts on improving familiarity and education of health care professionals on spirituality issues
- ✦ Incorporate spirituality into medical school curriculum

# Quality of Life (QOL)

- ✦ **Current Status** Quality of Life instruments have not been incorporated in patient care.
- ✦ **Practice Recommendations**
  - ✦ Consider using QOL instruments.
  - ✦ The McGill and the SEIQoL are validated
- ✦ **Research Recommendations**
  - ✦ Need for further validation of QOL instruments at end of life and investigate whether QOL-guided care provides improved outcomes

# Family Caregivers

## ★ Present Status

- ★ Caregivers are mentally distressed and physically exhausted

## ★ The Ideal Goal

- ★ Caregiving offers a rewarding experience and improves QOL of patient's and caregiver's wellness

## ★ Practice Recommendations

- ★ Proactive caregiver attention (education, counseling, and support) prevents caregiver burden

# Family Caregivers

## ✦ Research Recommendations

- ✦ Initiate prospective studies to develop caregiver risk assessment for those at high risk (high potential for distress/burden) and
- ✦ Develop proactive caregiver care programs and assess over the long-term to measure changes in outcome
- ✦ Develop caregiver's QOL and burden scales

## ✦ Policy Recommendations

- ✦ Provide Medicare and other insurance reimbursements for family caregivers who provide end-of-life care and
- ✦ Provide reimbursement for physicians who care for the caregivers of their patients

# Access of Quality Care

## ✦ Present Status

- ✦ Lack of coordination of multidisciplinary care
- ✦ Patients and caregivers are dissatisfied with fragmented care

## ✦ Practice Recommendations

- ✦ Develop a standard end-of-life care algorithm

## ✦ Research Recommendations

- ✦ Investigate the ideal timing of referral to hospice in ALS

## ✦ Policy changes

- ✦ Establish a “Center of Excellence” certification program
- ✦ Modify and expand Medicare guidelines for hospice use for patients with ALS

# Final Report

## INTRODUCTION:

- ✦ A case statement describing the need for the Workgroup and why the group convened
- ✦ The convening process

## WORKGROUP FINDINGS

- ✦ Identification of existing resources
- ✦ Identification of gaps

## RECOMMENDATIONS TO FIELD

- ✦ Practice Recommendations
- ✦ Research and program development recommendations (clinical, education, health systems)
- ✦ Policy recommendations

# Dissemination of ALS Workgroup Recommendations



# Summary and Conclusions

- ✦ **End-of-life care in ALS is part of the RWJ's continued commitment in promoting excellence in end-of-life care**
- ✦ **ALS Association functioned as a facilitator and assembled the ALS Peer Workgroup**
- ✦ **We looked at the end-of-life care in ALS in the broadest possible ways:**
  - ✦ **Current state clinical care**
  - ✦ **Ideal state of care**
  - ✦ **Recommendations**
    - ✦ **practice**
    - ✦ **research and program development, and**
    - ✦ **policy**

# Summary and Conclusions

- ★ **Seek endorsement from American Academy of Neurology and other ALS-related organizations**
- ★ **This effort will be highly complementary to the AAN Practice Parameter**
- ★ **Dissemination plans include:**
  - 1. a consensus or opinion paper,**
  - 2. special journal issues on end-of-life care in ALS**
  - 3. patient and caregiver educational material and management booklets**
- ★ **Common goal –**  
*Improve the end-of-life care in ALS*

# Filling the Gaps in End-of-Life Care in ALS: Report of the RWJ Foundation ALS Peer Workgroup

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*Rup Tandan, MD, Burlington*

*The American Academy of  
Neurology, Denver, CO 2002*

# Conflict Of Interest

## Full Disclosure

We or our immediate family members has **NOT** or have **NOT** had a significant financial interest in, or other relationship with, the manufacturer(s) of any commercial product(s) related to the topic of presentation. This disclosure includes:

- a. Salaries
- b. Ownership
- c. Equity positions
- d. Stock options
- e. Royalties
- f. Consulting fees
- g. Honoraria for speaking
- h. Research grants
- i. Material support
- j. Other financial arrangements

# Present Reality

- ✦ Lack of familiarity in discussing end of life issues
- ✦ Delay in treatment... *“Too much too late ...”*
- ✦ Reluctance to treat the “futile” end of life patient
- ✦ Limited knowledge and experience-
  - ✦ use of pain-control medications
  - ✦ withdrawing life-sustaining treatment
- ✦ Distressed and exhausted caregivers
- ✦ Lack of coordination of multidisciplinary care
- ✦ Dissatisfaction with current fragmented care approach
- ✦ Lack of knowledge about ALS across specialties

**Robert Wood Johnson Foundation**  
**Promoting Excellence in**  
**End-of-Life (EOL) Care**

**ALS Association**

**ALS Peer Workgroup**

**Psychosocial Care**  
*Mark Bromberg, MD, Chair*

**Access of Care, Cost of Care,  
and Knowledge/Education**  
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**Ethics, Communication,  
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**Symptom Management**

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**Raul Mandler, MD, Washington, DC**

**Jane McCarthy, Calabassa Hills,  
CA**

**Robert G Miller, MD, San  
Francisco, CA**

**Hiroshi Mitsumoto, MD, New York,  
NY (Chair)**

**Theodor L Munsat, MD, Boston,  
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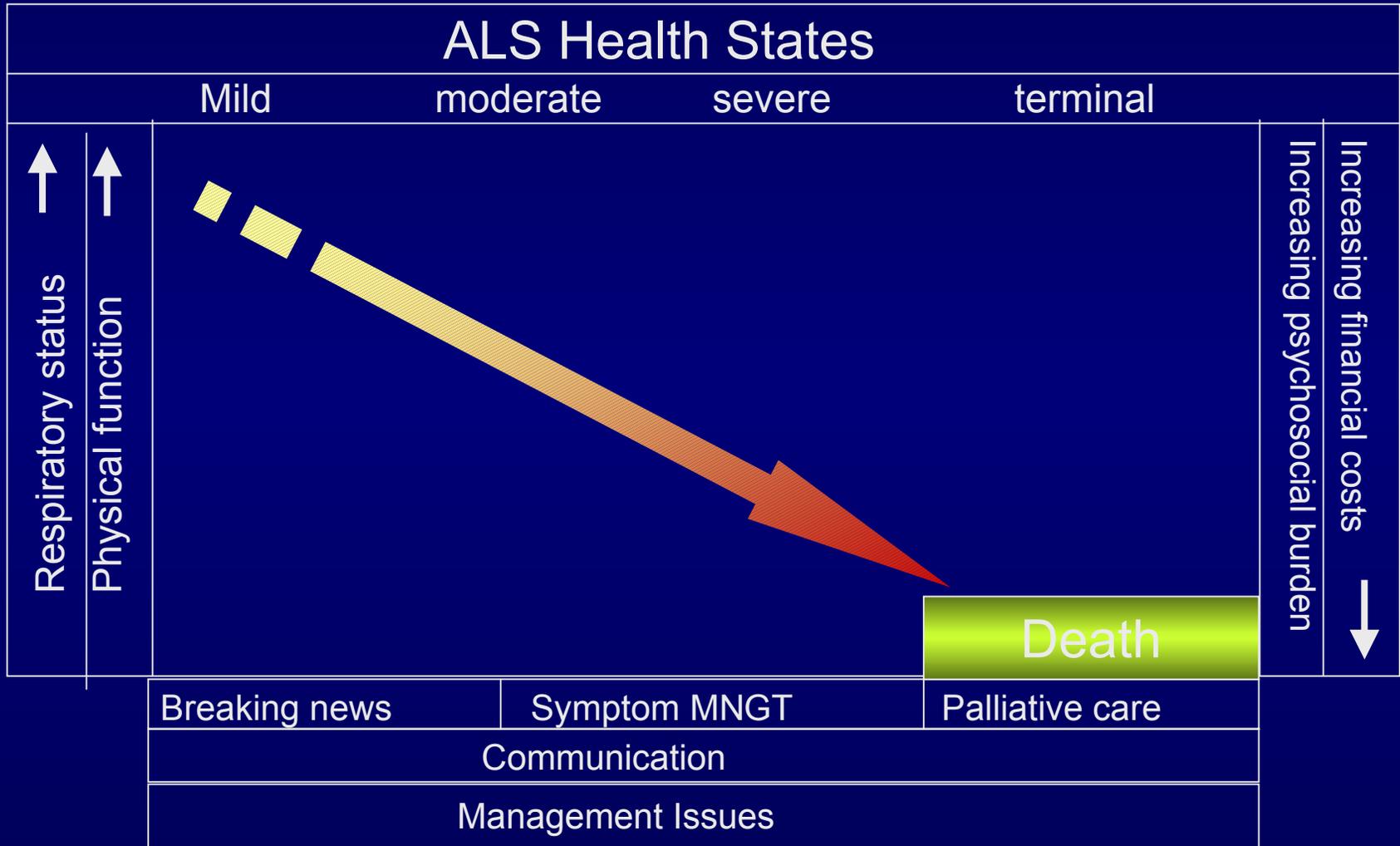
# Methods

- ✦ **Medical evidence and resources---the current state of care**
- ✦ **Gap analysis--- the gap between current care and ideal care**
- ✦ **Expert consensus**
- ✦ **Recommendations**
  - ✦ **Practice Recommendations**
  - ✦ **Research and program development recommendations (clinical, education, health systems)**
  - ✦ **Policy recommendations**

# Progress in the ALS Workgroup

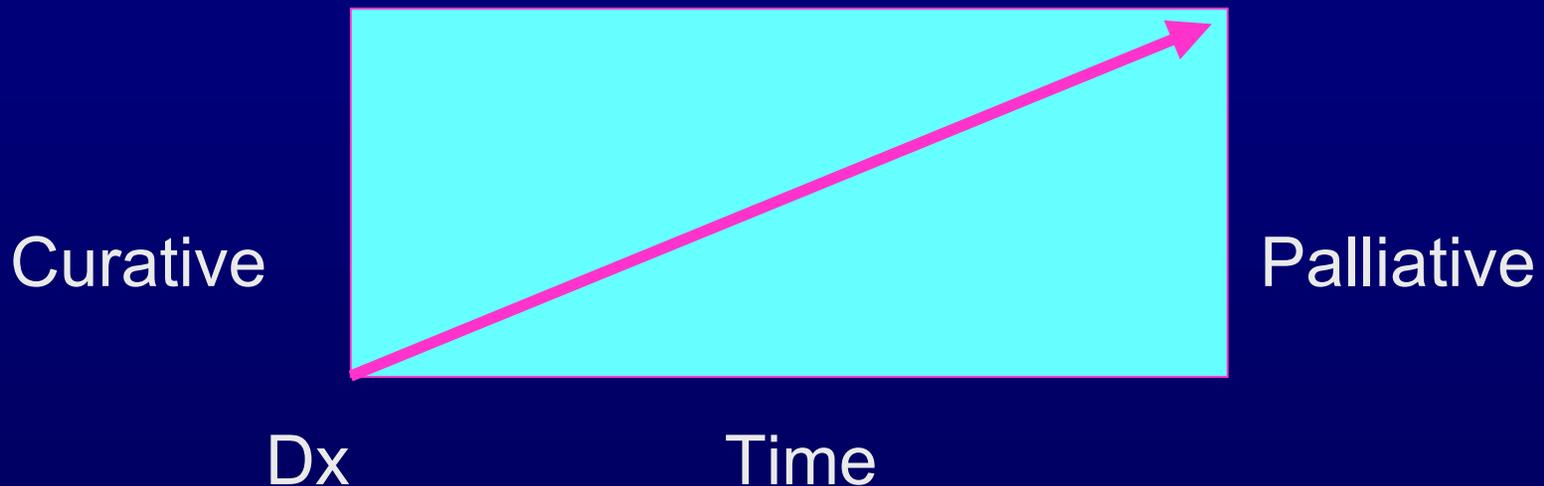
- ✦ Inauguration meeting at Airlie House, 5/2000
  - ✦ Overall goals, plan, process, and subcommittees
- ✦ Conference calls among the subcommittees
- ✦ Exchange the information via RWJ website
- ✦ Midterm meeting at Aarhus, 11/2000
- ✦ Individual subcommittee meetings in the summer
- ✦ Wrap-up meeting at Scottsdale, 11/2001
- ✦ An endorsement from the AAN Practice Committee
- ✦ Publications

# Window on ALS



# When does the end of life begin?

At the time of the diagnosis of ALS made?  
Sometime later, but when?



# The Operational Definition of EOL in ALS

## 6 “Triggers”

1. The patient or family asks – or “opens the door” for end-of-life information and/or interventions (elicited or spontaneous, verbal or non-verbal), or
2. Severe psychological and/or social or spiritual distress or suffering, or
3. Pain requiring opiates, or
4. Dysphagia requiring feeding tube, or
5. Dyspnea or symptoms of hypoventilation, forced vital capacity at 50% or less, or
6. Loss of function in two body regions

# Symptom Management

- ✦ **Nutritional care**
- ✦ **Respiratory care**
- ✦ **Pseudobulbar affects**
- ✦ **Communication impairment**
- ✦ **Depressive symptoms**
- ✦ **Pain management**
- ✦ **Insomnia**
- ✦ **Care of the dying patient**
  - ✦ **With or without ventilator**

# Psychosocial Care

- ✦ **Family Caregivers**
- ✦ **Spirituality**
- ✦ **Bereavement**
- ✦ **Quality of Life**
- ✦ **Overall Psychosocial Intervention**
  - ✦ **Hope while dying**
  - ✦ **Coping and counseling**
  - ✦ **Sexuality & intimacy**
  - ✦ **Needs of children**
  - ✦ **Dying & life closure**
  - ✦ **Ethnic and cultural difference**

# Family Caregivers

## ★ Practice Recommendation

- ★ Caregivers should receive proactive support

## ★ Research Recommendation

- ★ Initiate prospective studies to develop caregiver risk assessment for distress/burden
- ★ Investigate the most effective elements in caregiver support

## ★ Policy Recommendation

- ★ Provide Medicare (and other insurance) reimbursements for family caregivers who provide end-of-life care, and
- ★ Provide reimbursement for physicians who care for the caregivers of their patients

# Spirituality

## ✦ Present Status

- ✦ Spiritual needs are still largely neglected, even in the context of end-of-life care

## ✦ Practice Recommendations

- ✦ Incorporate spiritual care as an integral component of palliative care for the patients and their families
- ✦ Professionals involved in the care of patients with ALS should have spiritual care education

# Bereavement

## ★ Present Status

- ★ Most information available on bereavement is not specific for ALS/MND
- ★ Uniqueness of bereavement in patients with ALS (progressive with loss of function) and in caregivers (bereavement vs. relief and guilt)

## ★ Practice Recommendation

- ★ Clinics should offer bereavement support in several ways (the grieving process, letters of condolence at time of death, and offering bereavement support after death of the patient)

## ★ Research Recommendation

- ★ Basic data needs to be accumulated in patients and their caregivers in ALS

# Ethics, Communication, and Decision Making

## ☀ Practice Recommendations

- ☀ Improve physician's communication skills with patients/caregivers
- ☀ Improve physician's comfort and familiarity with end-of-life issues
- ☀ Promote a patient bill of rights

## ☀ Clinical Research Recommendations

- ☀ Analysis of timing, quality, quantity, and nature of the communication (between physicians and patients) and outcomes

## ☀ Policy Recommendation

- ☀ Improve the educational program at all levels

# Access of Quality Care, Cost

## ★ Practice Recommendation

- ★ Timely referral to hospice
- ★ Availability of adequate in-home care

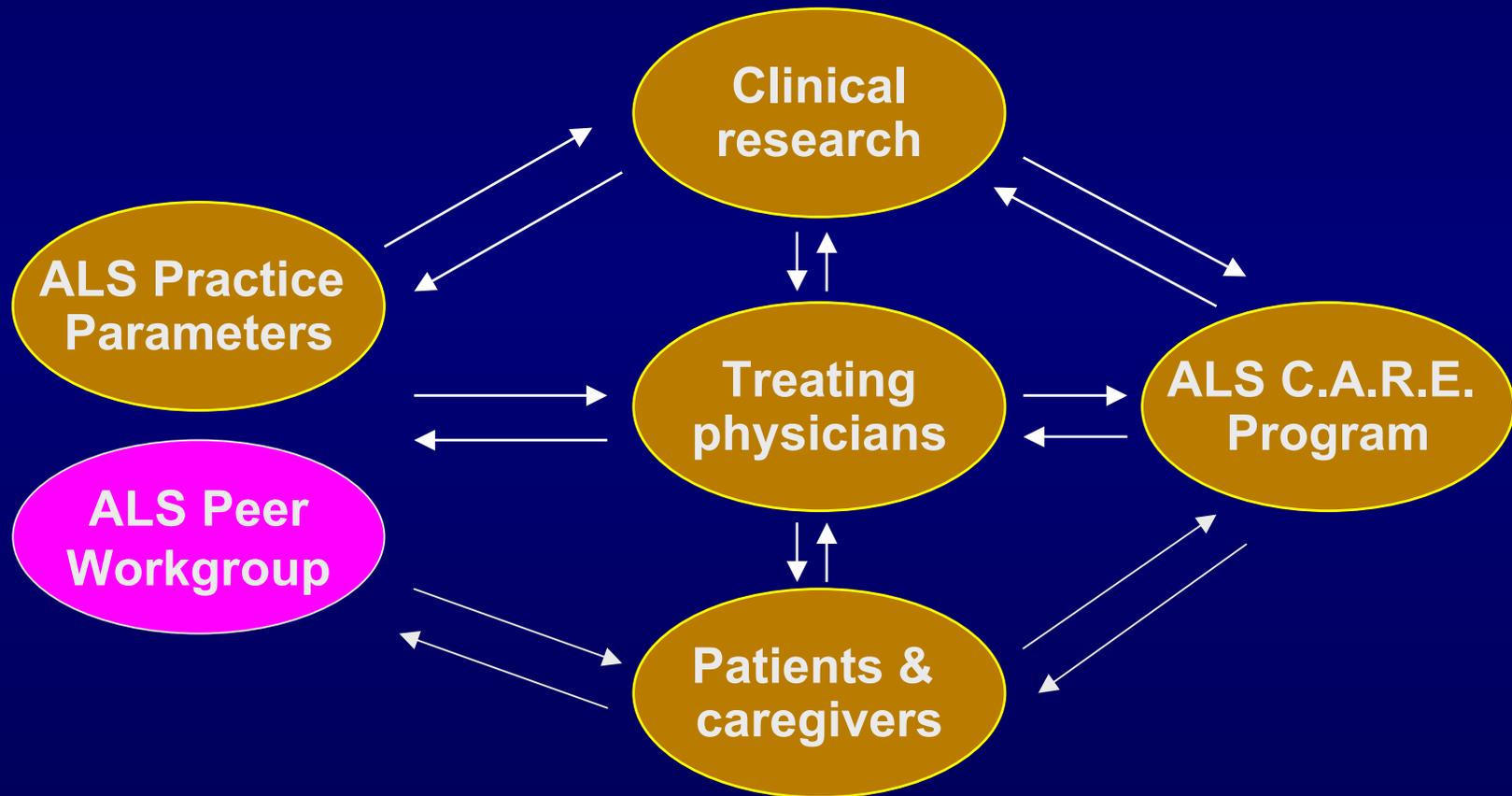
## ★ Research Recommendation

- ★ Evaluate criteria for referral to hospice based upon patient's need
- ★ Prospective cost-benefit and -effectiveness studies in ALS at end of life

## ★ Policy Recommendation

- ★ Modify the Medicare guidelines of hospice admission
- ★ Establish center of excellence concept in ALS

# Synergy Between Practice Parameter Recommendation and Outcomes Assessment



# ALS Peer Workgroup

## CONCLUSIONS

- 1. We have performed a “gap analysis” on the current end-of-life care in ALS.**
- 2. A series of evidence-based or consensus-based recommendations are provided in order to improve the end of life in ALS.**
- 3. Results from the Workgroups will be disseminated to the community (publications, etc.)**
- 4. The Long-term goals of the Workgroup are to:**
  - ✓ stimulate end-of-life research,**
  - ✓ broaden the evidence base on treatment during end of life, and**
  - ✓ improve the overall end-of-life care in ALS**