



**END-STAGE
RENAL DISEASE
WORKGROUP
FINAL REPORT SUMMARY**

Recommendations to the Field

PROMOTING EXCELLENCE IN END-OF-LIFE CARE
A NATIONAL PROGRAM OFFICE OF
THE ROBERT WOOD JOHNSON FOUNDATION

Completing the Picture of Excellence

In 1997, The Robert Wood Johnson Foundation launched a national program *Promoting Excellence in End-of-Life Care* with a mission of improving care and quality of life for dying Americans and their families. We soon realized that the metaphor of a jigsaw puzzle seemed apt in describing our efforts to expand access to services and improve quality of care in a wide range of settings and with diverse populations. No single approach would suffice—a variety of strategies, models of care, and stakeholders are necessary to successfully complete the picture. This monograph represents one aspect of our work and one piece of the puzzle of ensuring that the highest quality of care, including palliative care, is available to all seriously ill patients and their families.

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Alvin H. Moss, MD, ESRD Workgroup Chair
ESRD Workgroup Members

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END-STAGE RENAL DISEASE WORKGROUP MEMBERS

Barbara Campbell, MSW, ACSW
Patient Service Coordinator
ESRD Network #15
Denver, CO

Lewis M. Cohen, MD
Co-Medical Director
Psychiatric Consultation Service
Baystate Medical Center
Springfield, MA

William R. Coleman
Attorney at Law
Brooklyn, NY

Helen Danko, RN, CNN
Director of Dialysis Services
The Dialysis Center
Winthrop University Hospital
Mineola, NY

Richard Dart, MD
Staff Physician
Department of Nephrology
Marshfield Clinic
Marshfield, WI

Lesley Dinwiddie, MSN, RN
Nurse Practitioner
University of North Carolina
Chapel Hill, NC

Michael Germain, MD
Associate Professor
Western New England Renal
& Transplant Association
West Springfield, MA

Cathy Greenquist, RN
Nurse Practitioner
Baystate Medical Center
Greenfield, MA

Jean Holley, MD
Professor of Medicine
University of Rochester
Rochester, NY

Karren King, MSW, ACSW, LCSW
Nephrology Social Work Consultant
Kansas City, MO

Paul L. Kimmel, MD
Director Diabetic Nephropathy and
HIV Programs
NIDDK National Institutes of Health
Bethesda, MD

Jenny Kitsen
Executive Director
ESRD Network of New England, Inc.
New Haven, CT

Lori Lambert, MS, RD, CDE
Renal Nutritionist
DCI, Inc.
Boston, MA

John Leggat Jr., MD
Assistant Professor of Medicine
SUNY Upstate Medical University
Syracuse, NY

Sharon McCarthy
Nurse Practitioner
Western New England Renal
& Transplant Association
Springfield, MA

Alvin H. Moss, MD (Chair)
Professor of Medicine & Director
Center for Health Ethics and Law
Rober C. Byrd Health Sciences
Center, West Virginia University
Morgantown, WV

John M. Newmann, PhD, MPH
President
Health Policy Research & Analysis
Reston, VA

Marilyn E. Pattison, MD
Medical Director
Palliative Care Services
Franciscan Health System
Tacoma, WA

Erica Perry, MSW
Nephrology Social Worker
University of Michigan
Ann Arbor, MI

Susan Pfetscher, DNSc, RN
Associate Professor
Department of Nursing
California State University
Bakersfield, CA

David Poppel, MD
Nephrologist
Western New England Renal
& Transplant Association
Springfield, MA

Mohamed Abed Sekkarie, MD
Clinical Associate Professor
Department of Medicine
West Virginia University
Bluefield, WV

Dale Singer, MHA
Executive Director
Renal Physicians Association
Rockville, MD

Richard Swartz, MD
Professor of Internal Medicine
Nephrology
University of Michigan
Ann Arbor, MI



Most patients with end-stage renal disease (ESRD), especially those who are not candidates for renal transplantation, have a significantly shortened life expectancy. In comparison to the United States population as a whole, dialysis patients live about one-third as long as individuals without ESRD of the same age and gender. Additionally, 45 percent of new ESRD patients have diabetes, and many have other comorbid conditions including hypertension, congestive heart failure, ischemic heart disease, and peripheral vascular disease. According to the United States Renal Data System (USRDS) 2001 Annual Data Report, over 65,000 ESRD patients die each year. The unadjusted five-year probability of survival for ESRD patients on dialysis is only 39 percent. Consequently, the care of ESRD patients requires expertise not only in the medical maintenance of patients on dialysis, but also in palliative care that focuses on management of pain and other symptoms, advance care planning, and attention to ethical, psychosocial and spiritual issues related to starting, continuing, withholding and stopping dialysis.

In recognition of a growing interest in palliative care by clinicians, patients and families, the *Promoting Excellence in End-of-Life Care* national program of The Robert Wood Johnson Foundation created a national Peer Workgroup to rapidly assess the existing evidence base and available resources for improving the comfort and quality of life for dialysis patients, and to recommend strategies to advance palliative care for this patient population. The Promoting Excellence ESRD Workgroup, which met over a period of 18 months from March 2000 through October 2001, has completed its charge. Chaired by Alvin H. Moss, MD, Director of the West Virginia University Center for Health Ethics and Law and a nephrologist at West Virginia University School of Medicine, the workgroup consisted of 23 members, including nephrologists, nurses, social workers, administrators and ESRD patients.



In order to address the various issues, the ESRD Workgroup divided into three subgroups: Quality of Life, Quality of Dying, and Education.

The Quality of Life subgroup addressed the discordance between the life-sustaining technology of dialysis and the burdens of the symptoms of renal insufficiency and comorbidities common in ESRD. These comorbidities are often insufficiently appreciated at the outset by patients and families and incompletely described by clinicians. This subgroup examined ways to better identify factors that impact patients' quality of life. Once identified, these factors can be addressed to improve patient quality of life.

The Quality of Dying subgroup identified a paucity of literature addressing the quality of the end-of-life experience and care for ESRD patients, particularly from the perspectives of patients and families. Anecdotal information and studies suggest that the "quality" of the dying experience among dialysis patients is less than optimal. Factors contributing to this poor

experience include: inadequate advance care planning; inadequately treated pain and other symptoms; insufficient attention to emotional stress of patients and families and family dynamics; a general lack of patient/family/public education about end-of-life care; and failure to address issues of religion, race and cultural diversity as they relate to life completion and closure.

There is no consistent policy to honor the preferences of dialysis patients who do not want to undergo cardiopulmonary resuscitation, and more worrisome, policies of many dialysis units are either unclear on this point or prohibit honoring a legitimate Do Not Resuscitate (DNR) directive from an ESRD patient. Furthermore, a lack of information and misconceptions regarding the process of dying represent obstacles to optimum end-of-life care and decision-making for ESRD patients and their families.

The Education subgroup recognized that a key barrier to change in the dialysis community is a deficiency of knowledge about palliative care. The Education subgroup documented a lack of specific books or chapters on palliative care for ESRD patients. They also identified significant gaps in training programs and, consequently, in nephrologists' knowledge, attitudes, and practice skills in renal palliative/supportive care. At the root of these deficiencies in education and practice lies a culture of denial related to dying and death within dialysis units—one shared by nephrologists, staff, patients and families. The Education subgroup developed a curriculum program designed to build a knowledge base in palliative care among practicing nephrologists. The "Education for Nephrologists in End-of-Life Care" (ENEC) curriculum provides nephrologists with a "new language" on advance care planning, giving bad news, and incorporating spiritual issues into their practice as well as new knowledge and skills in pain and symptom management.



After considerable research, discussions and expert consultation, the workgroup recommends the following actions to improve the quality of palliative care provided to ESRD patients and families:

CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)

The Promoting Excellence ESRD Workgroup asks CMS to:

- Update “Conditions of Participation” for dialysis units to include requirements for advance care planning and the provision of palliative care.
- Collect data on hospice utilization on the 2746 form.
- Allow the Medicare hospice benefit to be applied to ESRD patients who are certified by their physicians as terminally ill, but who choose to continue dialysis until they die.
- Work in conjunction with hospice and the ESRD Networks to develop manuals and training for clinicians regarding coordination of dialysis and hospice care for ESRD patients.
- Require dialysis unit staffing to provide reasonable time for social workers to counsel patients on psychosocial issues that surround end-of-life care.

NATIONAL INSTITUTE OF HEALTH, NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

The National Institute of Health and National Institute of Diabetes and Digestive and Kidney Diseases are asked to make the following adjustments to U.S. Renal Data System annual reports:

- Provide more data on patient survival, including Kaplan-Meier estimates of patient survival based on ESRD diagnosis, patient age at the start of dialysis, and comorbid conditions.
- Expand data regarding ages and comorbidities of patients who are withdrawn from dialysis.
- Report data on hospice utilization and identify regional differences.

NEPHROLOGY RESEARCHERS

The nephrology research community is asked to:

- Study the extent to which hospice is utilized, the barriers to utilization and the outcomes of hospice care for ESRD patients.
- Identify factors associated with patient perceptions of quality of life and life satisfaction.
- Develop health-related quality of life tools that examine ESRD patient perceptions and subjective experience of their lives and ESRD treatment. These measures would encompass psychosocial status and support, patient satisfaction, and spiritual issues.
- Evaluate the relationships between quality of life assessments and patient outcomes to determine causal factors that contribute to quality of life.
- Identify, implement and evaluate interventions that improve quality of life.
- Apply quality of life assessment tools to distinguish patients with poor quality of life and employ

specific, corresponding interventions that have been demonstrated to be effective in longitudinal outcome studies.

- Assess prevailing knowledge and attitudes among ESRD patients and bereaved family members related to end-of-life care; identify specific misconceptions and information gaps.

NEPHROLOGY EDUCATORS

Nephrology educators are encouraged to:

- Develop a “train the trainers” course, using an adapted version of the ENEC (Educating Nephrologists in End-of-Life Care) program to train Program Directors, Network Medical Review Board Chairs and Medical Directors of dialysis units.
- Include training in palliative care in nephrology fellowship programs, Board review courses and nephrology textbooks.
- Develop curricula on end-of-life care for dialysis patients for nephrology nurses, social workers, dietitians and technicians to encourage multi-disciplinary, comprehensive treatment.
- Include palliative care content on performance tests for knowledge and competencies/skills for all clinical dialysis staff.

NEPHROLOGY CERTIFYING BOARDS

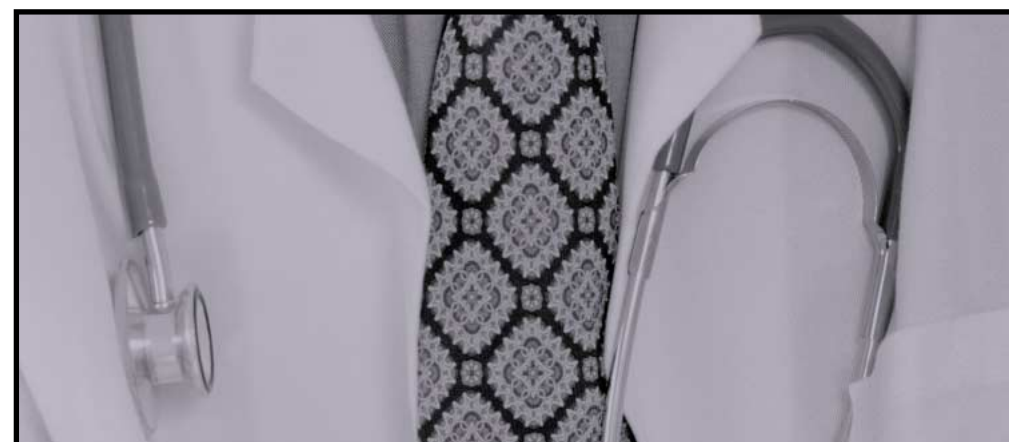
Nephrology certifying boards are encouraged to:

- Include palliative care content on certifying examinations for Nephrology Board certification examinations.
- Include palliative care content on specialty certifying examinations for nephrology nurses, social workers and technicians and all clinical disciplines associated with care of ESRD patients.

DIALYSIS CORPORATIONS

Corporations that own and operate dialysis units are called upon to:

- Incorporate palliative care policies and practices into dialysis unit services.
- Adopt policies regarding CPR in the dialysis unit that respect patients’ rights of self-determination, including the right to refuse CPR and to have a DNR order issued and honored.
- Implement bereavement programs for the benefit of other patients, patients’ families and dialysis staff.
- Support the development of peer mentoring in their dialysis units to enhance patient education and support.
- Foster the role of social workers in providing psychosocial support in their dialysis units, ensuring that dialysis social workers have sufficient time to offer psychosocial guidance and support for dialysis patients and their families.





DIALYSIS UNITS

The Promoting Excellence ESRD Workgroup recommends that Dialysis Units:

- Educate patients and families about palliative and end-of-life care.
- Institute palliative care programs that include pain and symptom management, advance care planning, and psychosocial and spiritual support for patients and families.
- Adopt policies regarding CPR in the dialysis unit that respect patients' rights of self-determination, including the right to refuse CPR.
- Support the development of peer mentoring in their facilities.
- Develop and implement bereavement programs.

ESRD NETWORKS

ESRD Networks can:

- Incorporate end-of-life care/palliative care concepts into educational outreach programs.

- Conduct educational sessions for dialysis providers on the medical, ethical, legal and practical issues surrounding CPR in the dialysis unit.

ESRD PATIENT ADVOCACY ORGANIZATIONS

Organizations providing patient education and advocacy, such as the American Association of Kidney Patients (AAKP) and the National Kidney Foundation (NKF), are asked to:

- Develop patient-centered, sensitive, culturally relevant educational materials that are candid about the life-limiting nature of ESRD. These materials would convey the importance of patient choice about control over treatment, especially as complications of ESRD and comorbid conditions arise. These choices include advance directives, DNR orders, palliative care and hospice, as well as considerations related to dialysis withdrawal.
- Work with nephrology educators to distribute brochures and information

about common symptoms, treatment and available resources for ESRD patients and their families relative to the patients' final days/hours of life.

- Promote the use of peer mentors to assist patients in their adjustment to ESRD and its treatment and to help them become knowledgeable about a full range of options as they prepare for the end of life.

NEPHROLOGY HEALTH CARE PROFESSIONALS

To enhance quality of life, nephrologists and other members of the renal care team are asked to:

- Incorporate interventions found to be effective in improving quality of life of ESRD patients into their own clinical practice and into routine care on dialysis units in which they practice.
- Routinely invite patients to express their end-of-life care preferences in the required semi-annual short-term and annual long-term care planning meetings.
- Encourage patients to communicate their preferences to family and to complete written advance directives.
- Refer dying ESRD patients to hospice and/or adopt a palliative care approach to their management.

PUBLIC AND PRIVATE FUNDERS OF RESEARCH

The Promoting Excellence ESRD Workgroup calls upon funders of research in nephrology to:

- Support research in pain and symptom management for ESRD patients.
- Support research on patient perceptions of quality of life in ESRD, including research that identifies reasons for high dialysis withdrawal rates.
- Support research that identifies interventions that result in improved patient satisfaction with dialysis.
- Support research on the impact of peer mentoring on psychosocial measures of

ESRD patient quality of life and on end-of-life care planning among renal patients.

ADVANCES IN EXCELLENCE IN END-OF-LIFE CARE

The Promoting Excellence ESRD Workgroup made considerable progress in bringing palliative care issues to the attention of the nephrology community. The Chair of the American Board of Internal Medicine Subspecialty Board on Nephrology invited the group to submit questions on end-of-life care for the board certification examination, five of which are included for the first time in the 2002 examination. In addition, the Renal Physicians Association (RPA) and the American Society of Nephrology (ASN) revised their joint position statement on Quality Care at the End of Life, building upon resources from the ESRD Workgroup and encompassing salient recommendations by the workgroup.

Key accomplishments of the Promoting Excellence ESRD Workgroup include:

- Establishing an initial evidence base of dialysis patient and family experience pertinent to comfort, quality of life and end-of-life care.
- Expanding relevant clinical resources available to nephrologists and dialysis clinical staff.
- Making recommendations to correct identified deficiencies and rapidly advance the integration of palliative care within dialysis practice.

In achieving these goals, the *Promoting Excellence in End-of-Life Care* ESRD Workgroup has begun a process that will lead to major, lasting improvements in the clinical care and support provided to dialysis patients and their families, through the end of life.

End-Stage Renal Disease Workgroup Full Report

The enclosed CD-ROM contains the ESRD Workgroup's Full Report, also available at www.promotingexcellence.org. The CD-ROM's contents are as follows:

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PROMOTING EXCELLENCE IN END-OF-LIFE CARE

A NATIONAL PROGRAM OFFICE OF
THE ROBERT WOOD JOHNSON FOUNDATION

1000 East Beckwith Avenue
Missoula, MT 59812
406.243.6601 Phone
406.243-6633 Fax
excell@selway.umt.edu
www.promotingexcellence.org