

# Collaborative Communique

A publication of the Georgia Collaborative to Improve End-of-Life Care

## Collaborative Co-Produces a Television Special Called "Final Choices"

Public television has recently focused on the great divide between the kind of care Americans say they want at the end of life and what our culture currently provides. The focus had both national and local scope, with a series from PBS as well as one from Georgia Public Television (GPTV), who shared producing credits with the Georgia Collaborative to Improve End-of-Life Care.

PBS premiered their series in September of this year with Bill Moyers at the helm and titled *On Our Own Terms: Moyers on Dying*. Two years in

production, this four-part, six-hour series took a hard look at the national effort to improve end-of-life care.

Each program is devoted to different issues related to end-of-life care. They are:

- Program 1: *Living with Dying*. Through the personal accounts of people facing death, this episode explores the choices we make at the end of life.
- Program 2: *A Different Kind of Care*. This episode introduces viewers to palliative care doctors and their patients, as they work hand-in-hand to make

(Continued on page 6...)

### In This Issue...

Collaborative Co-Produces a Television Special Called *Final Choices* ..... 1

Continuing to Lay the Groundwork for Change ..... 2

Consortium's Survey Informs Future Study ..... 3

The Health Policy Center Teams Up With The Georgia Academy of Family Physicians ..... 4

Research on the Insurance Industry and End-of-Life Care ..... 5

Recent Speaking Engagements ..... 7

# Continuing to Lay the Groundwork for Change

Dear Readers:

At the start of a new millennium, the work of the Georgia Collaborative to Improve End-of-Life Care continues to make considerable progress. As you will read in this issue of the *Collaborative Communiqué*, many of our recent efforts lay the groundwork for research and projects that will inform our work for the next couple of years.

The airing on PBS of “Final Choices,” a television special co-produced by the Collaborative, coincided with Bill Moyers *On Our Own Terms: Moyers on Dying*. As ratings indicate that many tuned in during the series, and, we are excited about the increased exposure to not only the issue of end-of-life care but also to the changes taking place here in Georgia. Reaching more of the public will only help broaden the conversation, which will, in turn, help transform our cultural expectations around end-of-life care.

The Health Care Ethics Consortium of Georgia continues to conduct its research on the end-of-life practices of Georgia’s health care professionals. Through the Consortium’s continued study, we are learning where education and policy change might improve the

efforts of those professionals who care for patients at the end of life. Their study is expansive and as they learn more, so will we be able to inform the decision-making of administrators, policy-makers, and health care professionals.

The research of the Collaborative’s Insurance Committee is also continuing to shed light on the many facets of end-of-life care. In this case, we are learning how the insurance industry provides coverage for such care as well as identify any insurance-related barriers to quality care for the dying.

Finally, the Health Policy Center has begun a project with the Georgia Academy of Family Physicians in

order to improve physician education on care at the end of life. This is a significant collaboration and will have far-reaching effects for the relationship between physicians and their terminal patients.

It is too early to report the results from many of these projects. However, they represent the process of change and the promise of a better health care system for Georgia’s patients and their families. I am proud of these efforts and the work we continue to do together.

Thank you for your support,

Jim Ledbetter ♦

During the upcoming weeks and months, CRITICAL *Conditions*<sup>SM</sup> will be exploring opportunities for expanding its project services beyond the current pilot communities. The project will be seeking health systems and other organizations interested in taking the lead on final health care planning in their communities. There are many advantages for the new communities taking part in the CRITICAL *Conditions*<sup>SM</sup> project. To date, the project has been very successful in increasing public awareness and institutional change around end-of-life care. CRITICAL *Conditions*<sup>SM</sup> will carry into its project expansion a vast resource of lessons learned during the past two years of working in the pilot communities. This accumulation of experiences will help institutions and organizations develop sound planning and best practices to implement a CRITICAL *Conditions*<sup>SM</sup> project.

In order to provide continuous support for the CRITICAL *Conditions*<sup>SM</sup> project, there is an enrollment fee that includes access to all the CRITICAL *Conditions*<sup>SM</sup> materials, program consultation, and extensive, on-site training. Anyone interested in bringing CRITICAL *Conditions*<sup>SM</sup> to his or her community may contact Georgia Health Decisions at 1-800-544-5751.

## Consortium's Survey Informs Future Study

In the fall of 1999, the Health Care Ethics Consortium of Georgia surveyed the 120 Georgia health care organizations comprising its past and present membership. This survey was the first step in the Consortium's efforts to draw a detailed portrait of current practices around end-of-life care in institutions across the state.

The survey focused on professional practices around advance directives, pain management – including both the assessment of pain and the kind of interventions currently in use, palliative care, family support, continuity of care, and hastened death. The Consortium is in the process of finalizing a report highlighting the findings from this preliminary survey; the report will be published at the end of the year.

The Consortium will utilize findings from the preliminary study to expand its research in order to better understand the end-of-life practices of Georgia's health care professionals. This month a second, more detailed, survey will be sent to a wider group of health care professionals, including a select sample of

Georgia's physicians, nurses, social workers, and chaplains, all of whom provide care for patients at the end of life.

Findings from the first survey will help inform the structure and content of the more

expansive study. For example, responses from the initial survey indicate that many respondents define advance directives very broadly, even including documents such as organ donor cards. Knowing this helps researchers begin refining the next set of questions to better understand how such broad definitions govern discussions around, and implementation of, advance directives in various health care settings. Results should give researchers some ideas of where there may be opportunities for education and policy change.

The Consortium hopes to have data from the second survey analyzed by the summer of 2001. Ultimately, the Consortium hopes to provide an increased understanding of health care professionals'

practices and attitudes around end-of-life care. Both the Consortium and the Collaborative, as well as health care institutions and professionals throughout the state, will benefit from this growing knowledge as it will help identify opportunities for improving care

through practice, policy changes, and/or educational programming.

For more information, contact the Health Care Ethics Consortium at 404-727-1247. ◆

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***The third annual Georgia Collaborative to Improve End-of-Life Care Conference has been scheduled for June 8, 2001. The conference will focus on "best practices" regarding the delivery of end-of-life care that have been identified through the Collaborative's work in the last three years. The conference will be held in Atlanta at the Loudermilk Center. More details will be made available closer to the conference date. For more information, contact Glenn Landers at 404-463-9562.***

# The Health Policy Center Teams Up With the Georgia Academy of Family Physicians

The Health Policy Center has begun a three-year project in conjunction with the Georgia Academy of Family Physicians. The project involves working with the Academy's statewide membership of 1200 family practitioners in order to improve physician education on the issues around death and dying. John Berglund, Executive Director of the Academy, explains: "Our work with the Georgia Health Policy Center is significant because family practitioners are not only general practitioners, but outside of Atlanta they are sometimes the only doctor serving a certain area. Many of them provide a great deal of geriatric care, so it is a natural collaboration to begin looking at ways to increase knowledge of end-of-life issues."

The Health Policy Center will oversee the facilitation of educational programming through seminars at the Academy's two annual conferences over the next three years. The most recent conference took place in early November, with over 300

physicians in attendance. A six-hour time slot, comprised of hour-long seminars, was devoted to end-of-life issues.

The seminar topics were drawn from the American Medical Association's program titled Educating Physicians on End-of-Life Care

(EPEC). Those topics were: *Communicating Bad News, Withholding and Withdrawing Life-Sustaining Treatment, Common Non-pain Symptoms, Management of Chronic Pain in Terminal Illness*, and, *The Last Hours of Living*. The seminars were led by the following individuals:

- Michael A. Ashburn, M.D., M.P.H., Professor of Anesthesiology at the University of Utah. Dr. Ashburn is the Medical Director of the Pain Management Center at the University of Utah and the Director of Pain

Management at Primary Children's Medical Center.

- Perry Fine, M.D., Professor of Anesthesiology at the University of Utah and Associate Medical Director of the Pain Management Center.
- Dr. Richard J. Ackermann, M.D. Professor of Family Medicine, Mercer University and the Director of the Family Practice Residency Program at the Medical Center of Central Georgia.

*"Family physicians, particularly those in rural practice, often serve as attending physicians for patients and families involved in terminal illness. These seminars will help Georgia doctors provide more competent and compassionate care at the end of life."*

The seminars were well attended, with each drawing between 30 and 80 attendees. Further, participant response to the seminars was overwhelmingly positive, as indicated in program evaluations. After each seminar, interesting and lively discussions took place, focusing on ethics, management of chronic pain in the context of legal restraints, and on issues around spirituality and dying. When asked about the conference, Dr. Ackermann

(Continued on page 8...)



# Research on the Insurance Industry and End-of-Life Care

For the last year and a half, the Collaborative's Insurance Committee has been conducting research that will shed light upon the relationship between Georgia's health insurance industry and end-of-life care. The focus of the research has not only been the private insurance industry, but also the state Medicaid and federal Medicare systems.

A report, scheduled for completion by the end of January, 2001, will discuss two types of findings about insurance and end-of-life care in Georgia.

First, it will include an overview of the findings that emerged from a survey, conducted last year, of all the insurance companies in the state, as well as, Medicaid and Medicare. The survey responses have been gathered and analyzed, leaving the Committee with a snapshot of end-of-life benefits held by 80-90% of all insured Georgians. This includes the percentage of those whose insurance covers important major categories of end-of-life related services, the level of that coverage, the nature of the services actually covered within a category, their associated costs, and how insurance

companies and systems structure eligibility requirements so that patients can access those services. The survey asked about a number of specific services, including what a company's procedure is for working with a patient at the end of his or her life. Consequently, the Committee can now identify the percentage of Georgians who have access, within coverage, to a service like hospice care, what is included in that care, and whether that benefit provides adequate coverage.

Secondly, the report will include a discussion of a wide range of insurance-related barriers to optimal end-of-life care. These barriers were identified through an in-depth series of interviews with providers from across the state. Through group discussions, feedback sessions, and one-on-one interviews, researchers were able to talk to a large sample of providers that included staff and administrators in nursing homes, hospitals, home health care agencies, and hospices as well as pharmacists and physicians in private practice.

Research yielded a series of barriers that, based on providers' perceptions, are created by the health care coverage provided for end-of-life services, as well as

some created by other factors such as the way providers are paid, and the amount, for such services. An example of a barrier to optimum coverage is the way home health care is offered in many private insurance packages. For many, in order to access the benefit of home health services, a patient must be completely home bound and require skilled nursing services. This is of little use to the relatively large population of people who are very ill and dying, but not necessarily home bound as defined by the insurance industry. Also, many people at the end of life don't have a skilled need, but have a series of other home care needs that fall outside the scope of skilled care.

Other examples of the barriers that providers identified include: limited levels of coverage for hospice, the lack of a respite level of care within hospice benefits, administrative structures and requirements that make Medicaid patients very unattractive to hospice providers, new payment methods and rates that discourage referral of nursing home patients to hospice, and the general low level of Medicaid reimbursement. And, notably, many providers identified as a barrier the

*(Continued on page 7...)*

# Collaborative Co-Produces a Television Special, Cont.

(Continued from page 1...)

the dying process more tolerable.

- Program 3: *A Death of One's Own*. The debate over physician-assisted suicide is addressed in this episode, where the critical issue is less the right to die, than the way to live when choices are circumscribed by practical realities.
- Program 4: *A Time to Change*. This episode introduces viewers to both caregivers and policy reformers who are working at providing better end-of-life care.

To complement the Moyers series, GPTV and the Collaborative co-produced a special called *Final Choices*, which was hosted by Leigh Green, a well-known and respected Atlanta journalist who has been diagnosed with incurable cancer. *Final Choices* examines the difficulty around making end-of-life decisions and encourages viewers to actually make these decisions while they are still physically capable. The series explores everything from the practical decisions around legal

issues, to the more philosophical questions of when to stop seeking curative treatment and move to comfort treatment, to weighing treatment against its impact on one's remaining quality of life.

*Final Choices* is comprised of two hour-long shows, with the first titled "Valley of the Shadow" and the second, "Changing a Culture." The work of the Collaborative as well as the CRITICAL Conditions<sup>SM</sup> project was featured prominently throughout the series. In fact, since the broadcast, CRITICAL Conditions<sup>SM</sup> has received requests for over 200 Planning Guides. The Collaborative's website, [www.gaeolcare.org](http://www.gaeolcare.org), also saw an increase in usage after the shows aired.

Production of *Final Choices* was made possible by grants from Blue Cross, Blue Shield of Georgia, The Georgia Health Policy Center, The Georgia Hospice Organization, GHA: An Association of Hospitals and Health Systems, The United Hospice Foundation, The Georgia Health Foundation, Emory Health Care, Northside Hospital, and Merck Pharmaceuticals.

According to local Nielson ratings reports, the program was seen by almost 450,000 Georgians. And, it was the highest rated show ever for GPTV in its time slot, despite its airing at the same time as the popular Emmy awards show. This is very encouraging to the Collaborative, whose members and partners work hard to increase exposure to, and better inform the public about, issues around end-of-life care.

If you missed either episode of *Final Choices*, copies can be obtained by contacting the Georgia Health Policy Center at 404-463-9562, or via e-mail at [mail@gaeolcare.org](mailto:mail@gaeolcare.org). Or, you may send a check for \$6.00 per episode, made payable to the Georgia State University Research Foundation to: Final Choices Video, c/o The Georgia Health Policy Center, One Park Place South, Suite 660, Atlanta, GA 30303.

Copies of the *On Our Own Terms* series can be obtained from Films of the Humanities (1-800-257-5126). Additionally, a website devoted to the series and to end-of-life care in general can be located at [www.pbs.org/wnet/onourownterms](http://www.pbs.org/wnet/onourownterms). ◆

# Recent Speaking Engagements

Dr. James Cooney, Associate Director of the Georgia Health Policy Center, and Glenn Landers, a Health Policy Analyst, have recently been invited to speak at the following venues on issues regarding end-of-life care.

- *“Conversations on End-of-Life Care”*  
**Georgia Oncology Social Workers**  
Dr. James Cooney & Glenn Landers
- *“Improving Continuity of Care among Georgia Nursing Facilities and Communities”*  
**Georgia Medical Directors Association Meeting**  
Dr. James Cooney
- *“Methodology for Hospital CEO’s to Identify Opportunities for Improving End-of-Life Care in Georgia”*  
**Georgia Hospital Association: An Association of Hospitals and Health Systems, 2000 Annual Summer Meeting**  
Dr. James Cooney

- **Association of Health Services Researchers Annual Meeting**  
*Repetitive Patterns for Inter-Institutional Transfers Among Nursing Home Patients*  
Dr. James Cooney & Glenn Landers
- *Panel Topic: “Health Statistics in the 21<sup>st</sup> Century”*  
**Institute of Medicine Invitational Symposium Honoring 50<sup>th</sup> Anniversary of the U.S. National Committee on Vital & Health Statistics**  
Dr. James Cooney

- *“Improving Continuity of Care and End-of-Life Care Planning”*  
**Georgia Nursing Home Association 48<sup>th</sup> Annual Meeting**  
Dr. James Cooney & Glenn Landers

## Research on the Insurance Industry and End-of-Life Care, Cont.

(Continued from page 5...)

lack of reimbursement/payment for providers to hold advanced care planning discussions with patients and families.

This report will indicate how well insurance systems provide and structure coverage for Georgians in need of end-of-life care services. At this stage in the process, researchers can make one very important determination: none of the benefit packages offered by private

insurance, Medicaid, or Medicare are structured to provide the range and quality of services necessary for those nearing death. This information will lay the groundwork for fundamental change in the way coverage is provided for those at the end of their lives. Therefore, these findings will be crucial in the Collaborative’s efforts to increase education, inform policy, and improve services.

For more information, contact Dr. Laura Good at 404-651-3533. ◆

# The Health Policy Center Teams Up With the Georgia Academy of Family Physicians, Cont.

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remarked: “Family physicians, particularly those in rural practice, often serve as attending physicians for patients and families involved in terminal illness. These seminars will help Georgia doctors provide more competent and compassionate care at the end-of-life.”

Though seminar topics for the upcoming meetings have yet to be decided, meeting planners have already committed similar

time blocks for topics on end-of-life care. Also, apart from the Academy’s meetings, regular mailings and issue papers will be disseminated to keep members informed of current research and findings.

Dr. James Cooney, speaking for the Health Policy Center, notes: “This project is exciting and rather significant as it represents the first time the Health Policy Center and the Collaborative are working with

such a large group of physicians to impact their work with patients in the realm of end-of-life.”

For more information on this project, contact Glenn Landers at 404-463-9562. ♦



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- Georgia Medical Care Foundation (404) 982-7847
- Health Care Ethics Consortium of Georgia (404) 727-1242
- Renaissance Research Project (404) 712-4444

Please look for more issues of the  
*Collaborative Communique* at:  
[www.gaeolcare.org](http://www.gaeolcare.org)