

## DIRECTOR'S REPORT

Center members have just completed a two-day conference entitled *Alzheimer's Disease and Related Dementias: Living our Challenges – Facing our Future*. Jointly sponsored with the local Alzheimer's Association and the Creighton University Center for Aging, Alzheimer's Disease and Neurodegenerative Disorders, the purpose of the conference was to assess the effects of Alzheimer's Disease and related dementias on individuals, families, professionals and policy makers and to help shape approaches to care and policy that take into account the economic, psycho-social and ethical challenges occasioned by these conditions.

No one was (or is) fully prepared for the devastation that Alzheimer's Disease and related dementias are bringing. Historically the health care and public health systems have responded vigorously to serious health problems that threaten physical, psychological and spiritual well-being. Their efforts have focused on prevention, cure, palliation, symptom control and – in recent years — life extension itself. Families traditionally have partnered with the health care system, rallying around loved ones in distress. Religious groups have provided sanctuary and understanding about the meaning of life, of suffering and of inevitable mortality.

The predicament of Alzheimer's Disease has developed as an unavoidable side-effect of our successes. Today's interventions, social support and policies, building on this historical bedrock, can claim many successes, among them the promise of a long life. Ironically these seeds of success also have yielded unintended consequences leading to unprecedented challenges for patients, families, professionals and society itself. One such consequence is that while more people today live longer than ever before in the history of humankind, many do so with Alzheimer's Disease that threatens to alter radically the promise of a good life in later years, to tear families apart and to call into question the deepest values of human life.

The conference is part of a larger international initiative, for while a large

fraction of patients with Alzheimer's Disease live in developed countries, possibly more than half live in developing nations. Understandably this disease is gaining recognition for its potentially devastating global health and social ramifications. In response to the dread incurred by this condition, families, religious groups, grassroots organizations, health care systems, the pharmaceutical industry, policy makers and others are searching for answers. At the same time, many in society who are socially marginalized by poverty or other conditions fear that even when answers are found they will not be included in the benefits, raising serious questions about justice.



CHPE members, along with several US colleagues and approximately twelve bioethicists, physicians, and policy makers from Western and Eastern European countries will undertake a prolonged probe into the topic of palliative care as a major focus of treatment for persons with Alzheimer's Disease. This fatal condition, characterized by dramatic alterations in cognition, memory, behavior and activities of daily living call for new dimensions of comfort care in the face of a downward course that can persist for a decade or more. With the support of a grant from the Greenwall Foundation (New York) combined with matching funds from Creighton University's Center for Health Policy and Ethics and the Department of Ethics, Philosophy and History of Medicine at the University of Nijmegen, The Netherlands, the twenty-five member Working Group will convene in Berg-en-Dal, The Netherlands, to:

- synthesize relevant US and European data and insights regarding the ethics of providing palliative care for persons with Alzheimer's Disease;
- identify existing arrangements and guidelines in the US and Europe that help promote a high quality of life for patients and their families;
- highlight differences in US and European approaches to palliative care that hinder effective dialogue and collaboration regarding Alzheimer's Disease;
- critically appraise the ethical arguments regarding present initiatives, guidelines and emerging trends on both sides of the Atlantic in the provision of palliative care for Alzheimer's Disease; and
- evaluate different national models for allocating palliative care resources.

The dialogue will focus on three areas: (1) types of comfort measures; (2) patient agency and the relationships in which family and social supports are realized; and (3) the demands of justice. The products from this joint effort will include an edited book by the participants of the Working Group and other articles, a set of ethical guidelines for palliative care in Alzheimer's Disease and a cross-cultural teaching module on the ethics of palliative care in Alzheimer's Disease for health professions students.

This major initiative, combined with several other complementary efforts worldwide, is timely. Predictions indicate that by 2025 more than 22 million people will have Alzheimer's Disease, and that number will double by mid-century. The World Health Organization has stated that fairness and justice demand palliative care be available to all.

*A critical component of our planning has been the presence of Professor Henk ten Have (see feature in this newsletter) as a Senior Visiting Fellow at CHPE this spring. He and I are the conference co-conveners with virtually every other participant deeply involved in some part of the planning and implementation. We are thrilled by such a fine opportunity to engage in this major activity that falls well within CHPE's focus on chronic illness and issues of justice.*

**Ruth B. Purtilo, Ph.D.**

# The Challenges of Public Health: Why Public? What Health?

The high incidence of Alzheimer's Disease, both in current numbers and as it is projected into the future (see Director's Report), forces us to look seriously at its impact on our society's healthcare needs. For the nature of Alzheimer's not only makes it a serious threat to those who suffer from actually having the disease, but to the millions whose lives are affected as caregivers. What are the implications for public health -- understood in its broadest sense -- of this disease? The key question we must first ask ourselves is: what makes public health "public?" Because it *is* public -- it affects the way we live together as a people. It must therefore, be concerned with equity and with justice. Because it relates to peoples' lives and the most elemental part of themselves -- because it touches what Aristotle termed "human flourishing" -- public health is a fundamentally moral enterprise.

The philosopher, Michael Walzer, reminds us that just distribution of goods is tied up with the meanings of these goods, and their meanings largely determined from their historical and cultural context. Within their various historical/cultural frameworks, societies allocate their goods according to different principles. Thus, in an earlier time in Western culture, land and purple clothing was distributed according to one's blood line, whereas today, it seems appropriate to distribute both by the Market Principle. While in assessing just distribution, we often look to whether or not allocations are made equally, Walzer suggests instead that injustice lies in using an inappropriate principle of distribution. Most of us would agree, for instance, that grades, honors, offices and voting privileges are all goods that are *inappropriately* -- and unjustly -- distributed by the Market Principle. One of the great moral challenges of our society is to determine by which principle we should apportion healthcare -- Need? Merit? Human Status?

Increasingly, the Market Principle infringes upon others for the allocation of all the goods of society, and seeks to be the sole principle behind the distribution of health and healthcare. This is the justice problem, for instance, behind the growing tendency to fund

research privately -- so that the question of *profit* determines what disorders will be explored; behind unfettered campaign contributions by the health industry; behind the faulty notion that employees, and hence "consumers" of healthcare plans, are its "customers" while employers are the real "customers"; behind the idea that assessment of healthcare is a consumer decision, in which people vote with their pocketbooks, thus disenfranchising the less advantaged among us.

## CHPE ROUNDTABLES

In the Fall of 2000 the Center for Health Policy & Ethics initiated the CHPE Roundtable Forum. **Dr. Eleanor Vogt**, an alumna of the Creighton University School of Pharmacy and Allied Health Professions and a senior fellow of the National Patient Safety Foundation, led a discussion of *Medical Errors, Their Causes, and Efforts to Reduce Them*. **Dr. Timothy Johnson**, medical editor of ABC television network, led a discussion entitled *Ethical Challenges of Health Reporting in the Media*. Interested faculty from across the Creighton campus and Omaha/Lincoln community members joined the discussions.

The purpose of the Roundtable Forum is to foster intellectual exchange in the Omaha Community, facilitate interdisciplinary communication and collaboration, give faculty members opportunities to try out new ideas and to learn about the scholarly interests of colleagues.

During Winter and Spring 2001, we have held three additional Roundtable discussions: CHPE member **Dr. Winifred Pinch** led a discussion about assisted reproduction entitled *Multiple Choice in Baby Making: Infertility Innovations or Exploitation?* **Dr. Henk ten Have**, Senior Visiting Fellow of the Center, presented for discussion *Medical Ethics in The Netherlands: Euthanasia, Substance Use and Abuse and Resource Allocation*. In April **Dr. Tom Nitsch** and **Dr. Ed Fitzsimmons**, from the Creighton University College of Business Administration, and **Dr. Patrick Murray** of the Creighton University Department of Philosophy of the College of Arts and Sciences, participated in a Roundtable on *Public/Social Goods and Private Goods*.

The justice considerations of public health should lead to concern about the evidence indicating poverty to be a risk for Alzheimer's Disease, as it is for other conditions.<sup>1</sup> The causal connections behind allegations of health disparities makes the link between poverty and specific diseases controversial. But whether or not poverty is an *antecedent* risk factor for this disease, it is most assuredly a *consequent* risk factor for the caregivers of persons with Alzheimer's Disease and other disorders. In 1997 the number of caregivers was 25 million and growing.<sup>2</sup> The implications of health policy and changes in healthcare practice (such as early release of patients from hospitals) mean that responsibility falls increasingly on family

members. It comes as no surprise that most often women are these caregivers, despite the fact that so many have jobs outside the home in addition to this task of caregiving. As in most other kinds of health care, the burden falls on the poor -- or the about-to-become-poor.

In one study<sup>3</sup> on the financial impact of caregiving, researchers found that more than thirty percent of the families (ninety-six percent of whom had private health insurance) lost most of their life savings, and twenty-nine percent lost their major source of income. In 1997 dollars, at a rate of \$8.18 per hour, the economic value of informal caregiving was \$196 billion, while expenditures for home health care were \$32 billion and for nursing home care were \$83 billion.<sup>4</sup>

These figures give new meaning to the recent announcement by HHS Secretary, Tommy Thompson, that, as part of the 2000 re-authorization of the Older Americans Act Amendments, the federal government will release \$113 million to help caregivers. Thompson seems to have missed the irony, not only of this embarrassing dollar figure, but of his remarks when he announced the funding: "We must do all we can to ensure that our older residents can remain at home and receive care from loved ones for as long as possible."<sup>5</sup> Few who are aware of the burden already placed on loved ones for home health care would rejoice at this news.

Rather, those who argue that we cannot afford the liability of health care for the elderly are right. We as a nation cannot afford health policy that debilitates, and renders poverty-stricken, those who -- cannily -- are asked to vote on such matters with their pocketbooks.

*Judith Lee Kissell, PhD*

<sup>1</sup>*The Social Determinants of Health*, Michael Marmot and Richard G. Wilkerson, Oxford U Press, 1999.

<sup>2</sup>Carol Levine, ed. *Always on Call*, New York: United Hospital Fund of New York, 2000. See Section II, particularly.

<sup>3</sup>*Always on Call*.

<sup>4</sup>*Always on Call*.

<sup>5</sup>HHS News, February 15, 2001.

# Palliative Care and Healthcare Ethics

Palliative care is "... the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families." This World Health Organization definition describes palliative care and points out that health care is not exhausted when the medical and technological possibilities of curing a disease become futile. At that moment, another type of care is necessary, with an emphasis different from curative and preventative medicine.

Palliative care is concerned with patients in the final stage of life. Curing the illness is no longer a real option. Patients as well as caregivers accept that death will prevail, usually in the not too distant future. Instead of prolonging life through medical interventions, quality of life becomes the main concern. Medical treatment aims at making the patient feel as comfortable as possible; treatment focuses on management of symptoms and relief of pain. Also, treatment becomes part of a wider strategy of care, where the medical symptoms are only relevant within the biography and the personhood of the patient.

A second characteristic of palliative care is that the patient and his relatives are at its center. Because the potential benefits of medical and technological interventions are limited, the patient should indicate what is meaningful to him. Fundamental questions confront the patient concerning the finiteness of human life. Human mortality now makes a forceful appearance in the patient's life. Queries concerning the meaning of life and death, as well as doubts about whether his life has been worthwhile, present themselves.

Patients may also worry over the future of their loved-ones when they themselves are no longer alive. Caregivers need to address these existential problems in interactions with patients and relatives. Caregivers must provide a different type of care than is usual within the health care setting. In order to meet the needs of the patients, co-operation between various categories of caregivers is necessary.

Palliative care's third characteristic is its intrinsic interdisciplinarity. Not only professionals are involved but family members, neighbors and friends as well. These volunteers guarantee continuity of care between the hospital, nursing home, hospice and home. Many patients prefer to die at home, but this wish requires an intensive co-ordination of professional and non-professional care.

These three characteristics demonstrate the intensive, comprehensive and problematic nature of palliative care. It is intensive, because it demands continuing involvement of

caregivers. It is comprehensive, because it requires a broad expertise, not only medical, to enhance the quality of life in the terminal phase. It is problematic, because many existential queries can emerge as well as ethical questions concerning the appropriate balance between the moral principles of individual autonomy, beneficence and non-maleficence and respect for human life.

The concept of palliative care is morally motivated. Its roots lie in the hospice movement that arose thirty years ago from a moral discomfort with mainstream medicine. Over the past decades, mainstream medicine as well as palliative care have changed significantly. Medicine is more attentive to the needs of the dying than thirty years ago, and palliative care no longer opposes mainstream medicine as stringently as in the past. However, the literature on palliative care, and specifically the literature on care for the dying, indicates that a continuum in the moral debate exists. Mainstream medicine continues to be dominated by an interventionist and activist attitude in the care of the dying, using biomedical, invasive technologies in the terminal phase. Furthermore, pain and symptom management seem to be insufficiently developed in many areas of medicine. Communication skills and the development of a sympathetic attitude are not major subjects in many educational programs. In other words, the concept of care is far from modern medicine that identifies itself with diagnosis and cure. Another argument holds however, that palliative care has become routine practice. Furthermore, it is argued, recent research in pain and symptom management has improved the quality of life of terminal cancer patients substantially and that present-day physicians have developed a more authentic caring attitude than existed some decades ago.

The literature on palliative care ethics suggests that the ethical debate between palliative care and mainstream medicine has reached an ideological stalemate. On the one hand, palliative care criticizes the moral principles of mainstream medicine. On the other hand, mainstream medicine is regarded as the basis for a further development of palliative care. Mainstream medicine claims to have introduced palliative care into daily practice and has a considerable interest in its development. Likely, these discrepancies are based on mutual misunderstandings due to lack of clarity about the concept of palliative care and a lack of insight into its organization in various countries.

Ethical research in this area has considerable practical import. At the moment, palliative care in many countries is at a critical crossroads. Health care planners must decide between developing palliative care into a

## Meet Henk ten Have...

Our fifth Senior Visiting Fellow, comes to us from the Netherlands where he is Professor of Medical Ethics and Director of the Department of Ethics, Philosophy and History of Medicine at the University of Nijmegen. Dr. ten Have received his doctorate in medicine in 1978 and in philosophy in 1983 from Leiden University. He brings a wealth of professional experience, including practicing as a physician in the Municipal Health Services, City of Rotterdam and as Professor of Philosophy in the Faculties of Medicine and Health Sciences, University of Limburg, Maastricht.



Dr. ten Have's current research focuses on ethical issues in palliative care. He is coordinator of the European Commission funded project "Palliative Care Ethics." He serves on numerous editorial boards and is editor-in-chief of the recently established journal, *Medicine, Health Care and Philosophy*.

specialized medical practice with chairs in universities, hospital departments or clinical units, or integrating it with established medicine, developing a palliative attitude among health care professionals (through education within existing medical disciplines, and through further professionalization of oncologists, general practitioners and nursing home doctors). Of course, there is not necessarily a dichotomy between these policy alternatives. Integration without specialization seems as undesirable as specialization without integration (Desmet 1996). One might argue that, in this development phase, specialization could serve further integration.

At present, palliative care is the target of new initiatives and policies in many countries. It is emerging as a new area of health care and in some countries as a new discipline. Because of demographic developments, an increasing burden of chronic diseases and moral debates about medical treatment at the end of life, the demand for palliative care will grow in the next decades. Due to the aging of the populations of various countries, chronic illness and disabling conditions such as Alzheimer's Disease will be more common. Foreseeing these changes, palliative care must be more adequately developed and more thoroughly considered within the practice of medicine and within the considerations of medical ethics.

*Henk ten Have, MD, PhD*

## Calendar of Events

CHPE will host the American Society for Bone and Mineral Research Working Group (Invited)

### *Ethics of Study Design in Osteoporosis Clinical Trials*

June 25, 2001

### **12th Annual Women and Health Lecture**

Speaker: Dr. Maryanne Stevens, RSM President, College of Saint Mary  
September 5, 2001, 7:00 – 9:00 p.m.  
Reception 6:30 – 7:00 p.m.  
Creighton University, Skutt Student Center Ballroom  
Free and open to the public

CHPE and the Katholieke Universiteit Nijmegen will host the **US-European Dialogue on the Ethics of Palliative Care for Alzheimer's Disease**

October 29 - 31, 2001  
Nijmegen, The Netherlands

### **Distinguished Lecture**

Co-sponsored by CHPE and Creighton University Dept. of Medicine  
Bernard Lo, MD, University California San Francisco  
*Clinical Research and Data Privacy Protection*  
October 10, 2001, 12:00 – 1:00 p.m.  
Morrison Seminar Room, Saint Joseph Hospital

Visit us online at:  
<http://chpe.creighton.edu>

## PLEASE WELCOME...

In November of 2000, **Jamie R. Waters** joined the Center as the faculty's administrative assistant. She assists the faculty with correspondence, course materials and the Center's various educational programs as well as helping with daily functions. She has a varied background working as a manager in the retail and customer service industry for several years in San Francisco and Stockton, California. Jamie came to Omaha with her husband Brian, who is finishing his first year in Creighton's School of Medicine, and their two dogs Emma and Boon. She enjoys being at CHPE and is looking forward to her new experiences in academic life and the subsequent weather changes of the Midwest heading her way.



Late in December, **Helen Shew** joined the Center as Senior Administrative Assistant. She has since been promoted to Program Coordinator and Community Development Liaison. As the first person to hold this position, she will be responsible for planning and organizing conferences and acting as CHPE's liaison with the Omaha community. She formerly served as Executive Director of the Omaha Community Foundation Womens' Fund and on-site director of an Offutt-based degree program offered through the University of Oklahoma. She has taught marketing at Peru State and elsewhere. She serves on the boards of several local service organizations.

## HONORS & AWARDS ...

Our congratulations to CHPE's **Amy Haddad, PhD, RN**, professor in the School of Pharmacy and Allied Health Professions and the Center for Health Policy and Ethics, who has been named a Carnegie Scholar for the Class of 2001. Dr. Haddad is one of just thirty faculty selected nation-wide for this honor. The class will work together to invent and share new conceptual models for teaching. Carnegie Scholars serve a one-year term while they investigate and document work on issues in teaching and learning in their field. Dr. Haddad will explore the impact that standardized patients have on the learning process and outcomes in the third-year pharmacy course, Ethics in the Health Care Professions.



CHPE is pleased to note that **Chris Perdue, MD**, who graduated from Creighton School of Medicine in May of this year, was awarded the **2001 Multi cultural Senior Award in Leadership** sponsored by the CU Black Employee Network. In addition to working on a fourth year ethics elective on the ethics of training surgeons, he has long worked with members of the Center on its focus on justice issues and concerns of minorities within the health care system.

### **FOCUS**

*FOCUS is published twice a year in the Spring and Fall by Creighton University's Center for Health Policy and Ethics, 2500 California Plaza, Omaha, NE 68178; Telephone (402) 280-2017*

Editor ..... Ruth Purtilo, PhD  
Associate Editor ..... Judith Lee Kissell, PhD  
Design, Graphics & Layout ..... O. R. Punla



Center for Health Policy and Ethics  
2500 California Plaza  
Omaha, NE 68178

Address Service Requested

#### **Faculty**

James Clifton, SJ  
Charles J. Dougherty  
Frank Dowd  
Beth Furlong  
Mark Goodman  
Amy M. Haddad  
Gail M. Jensen  
Judith Lee Kissell  
Robert J. McQuillan  
Roderick Nairn  
Richard L. O'Brien

Ruth B. Purtilo  
Winifred J. Ellenchild Pinch  
Linda S. Scheirton  
Jos V. M. Welie  
Gary Westerman

#### **Staff**

Rita Nutty  
Oscar Punla  
Helen Shew  
Jamie R. Waters

Non-Profit Org.  
U.S. Postage  
**PAID**  
Permit No. 227  
Omaha, NE