

POLICY FORUM

Alzheimer's Disease and Family Caregiving

Introduction

Gordon H. DeFriese, PhD, and Kristie Weisner Thompson, MA

Issue Brief: Alzheimer's Disease: The Cost and Who Pays?

Donald H. Taylor Jr., PhD

“Estimates provided by the National Alzheimer's Association indicate that 10% of the population over the age of 65, and almost 50% of the population over 85, have Alzheimer's disease. People with Alzheimer's disease live three to 20 years from the time of diagnosis...”

COMMENTARIES

The Alzheimer's Association National Policy Agenda

Bonnie Hogue Duffy, MA

Special Article: Alzheimer's and the Caregiver

Donald L. Madison, MD (with Myron H. Green)

Grieving the Living

Linda E. Jordan, DMin, CT

Family Care and Alzheimer's Disease: What Do We Know and What Can We Do?

Lisa P. Gwyther, MSW, LCSW

North Carolina's Support of Family Caregivers

Christine Urso, MSW

Effective Caregiver Support

Karisa Derence, MA

Managing the Patient with Dementia in Primary Care

Sindy McCrystle, ANP-C, MSN, and Darlyne Menscer, MD

Alzheimer's Disease: A Nursing Home Perspective

Ted W. Goins, Jr, and Lori R. Reid, BSW, CSW

Preparing Families to Make Informed Decisions about Long-Term Care

Sharon C. Wilder and Kathryn A. Lanier, MS

Dementia Care: An Outpatient, Community-based, Multi-disciplinary Approach

Virginia H. Templeton, MD

Alzheimer's Disease, Family Caregivers, and Faith in Action in North Carolina

Catherine O. Ahrendsen and Teepa Snow, MS, OTR/L, FAOTA

Dementia-Responsive Acute Care at Mission Hospitals in Asheville, North Carolina

Nancy Smith-Hunnicut

INTRODUCTION

Policy Forum: *Alzheimer's Disease and Family Caregiving*

The growth of North Carolina's older adult population (in size and proportion) has serious implications for families and for the state's health and human services programs. Public policy deliberations about the impending challenges associated with the growth of this population segment often begin with concern for how we will provide care for the increasing numbers of older adults who will suffer from various forms of dementia, including Alzheimer's disease. In this issue of the *North Carolina Medical Journal*, we have collected a number of perspectives on this large and looming set of issues.

We are fortunate to begin our discussion with an extensive Issue Brief prepared by Donald H. Taylor, Jr., PhD, a health policy specialist at Duke University. Dr. Taylor describes the demographic and epidemiologic trends related to dementia and Alzheimer's disease. He also directs our attention to some of the key public policy issues in need of immediate consideration (hopefully, before these issues overwhelm existing service delivery systems) and to the tremendous burden these issues pose for the families of those affected by Alzheimer's disease. Next, Bonnie Hogue Duffy, national policy specialist for the Alzheimer's Association in Washington, DC, provides an explanation of the Association's national legislative agenda. Their papers help to underscore the scope of the problem and make it clear that early diagnosis can be beneficial in a number of ways. They also emphasize the substantial public as well as personal benefit that could be gained from badly needed clinical therapeutics designed to delay disease onset. Being able to delay onset for even five years could dramatically lessen the personal and societal burden of this disease.

We are also pleased to include a substantial interview with caregiver, Myron H. Green of Durham, North Carolina, by our Contributing Editor, Donald L. Madison, MD. Dr. Madison brings the everyday burden and frustration of spousal care for a loved one with Alzheimer's disease to our attention. We are grateful to Myron Green for sharing his personal experiences with us. No one who reads Mr. Green's story will come away without deep respect and admiration for a caregiver or without an understanding of how important respite care and other helpful services can be to "round-the-clock" caregivers. Following this interview, we include several papers by well-known specialists in North Carolina who have either developed programs for the benefit of caregivers or who administer statewide programs offering such services. The hopeful message in these commentaries is that reliable sources of caregiver support exist, but they are often stretched thin, and their ability to meet the increasing need is in doubt. In addition, we include brief commentaries by specialists who have devoted careers to serving older adults through: primary care medicine and nursing, the provision of respite and bereavement services to caregivers, a variety of faith-based services, and/or long-term care facilities.

The concerns discussed in this issue of the *Journal* are ones that can have a major impact on the lives of all North Carolinians, regardless of social or economic status. Any time dementia or Alzheimer's disease threatens a close friend or family member, the effects of this diagnosis are likely to be all encompassing. Initially, families nearly always try to manage the care of a loved one in the home or community setting, but the burden of this decision often leaves the caregiver isolated; over-burdened physically, mentally, and economically; and with his/her own health at risk. It is apparent that family caregivers provide an enormous service to their ailing loved ones and to the state. We hope that organizing and presenting this information will generate thoughtful discussions among healthcare providers, patients, and policy makers that will ultimately enhance our family caregivers' ability to provide this important care and, in turn, enhance the state's long-term care capacity.

We invite our readers to share their reaction to these papers, and to these issues in general, in our Readers' Forum over the coming months.

Gordon H. DeFries, PhD
Editor-in-Chief and Publisher

Kristie Weisner Thompson, MA
Managing Editor