BOOK REVIEW


The issues of fundamental human dignity, the ethical foundations and the means by which we recognize, support, and sustain that dignity in the face of irreversible, progressive brain damage caused by Alzheimer disease (AD), are the animating subjects of this book of twenty-one chapters and two appendices. The contributing authors from Europe and the United States address these matters in six parts, including the neuropathological, clinical and related societal issues (Part I); European assessments of palliative care as practiced in the U.S. and in Europe (Part II); philosophical and theological discussions of autonomy, moral selfhood, and the practice of palliative care (Part III); decision-making, advance directives, the treatment of pain, interpersonal relations, euthanasia, and the like, and their relationship to clinical ethics (Part IV); ethics and organizational issues such as educational initiatives, laws, and allocation of resources (Part V); and research-based foundations for an ethical model of palliative care (Part VI).

It is no small challenge to write in one volume about AD from a neuropathological perspective all the way to a societal perspective and how our treatment of those who have been diagnosed, as well as those who will be diagnosed, might proceed best from both practical and ethical points of view. Yet, the authors of the individual chapters and the editors of the volume have worked admirably to meet that challenge. It is hardly a cliché to say that this book is more than the sum of its parts, for the authors at various points refer the reader to material contained in other chapters as that material relates to the discussions at hand. Thus, there is an interrelatedness among the chapters that leaves the reader not only with a keen appreciation of ethical, legal, and practical matters relating to people with AD and their families. There is also a poignant sense of urgency to meet the challenge of the

projected increase in the incidence of AD, along with a sense of how our meeting that challenge redounds to affect our own humanity.

Many authors discuss to one degree or another the fact that AD is a progressive and irreversible disease, that biomedical interventions have had only mixed and marginal success in slowing the progress of the disease, and that there is no cure. Given this state of affairs, and given the ever-growing numbers of people who are being diagnosed, the authors address the portentous issue of caring for these millions and their loved ones as the disease progresses toward the eventual death of the afflicted person. This discussion is focused through the lenses of ethical debates about how best to support aspects of human dignity and the relationship between traditional biomedical ethics and the practicalities of everyday life. Especially important here is the application of the hospice model of care and palliative care beyond the care of people suffering from cancer, or in a terminal stage of illness, to those with AD (ideally) throughout the course of the disease. The book points out how palliative care can ease the suffering both of the person with AD and his or her family. Recommendations for the treatment of the family as a unit that includes the person with AD, rather than merely the treatment of one person alone, are particularly enlightening and informing. These suggestions underscore the importance of a communal approach to dealing effectively with the ravages that AD inflicts on all concerned. The education of the family is a key component in this process. The communal approach is extended to society, for the way in which a society deals with its most vulnerable members reflects dramatically on the humanity of the society itself.

Among the major tensions that are addressed is that between guardianship on the one hand and autonomy on the other. We read about the heterogeneity of European development in this regard and the important distinctions between abstract ethical debates about preserving autonomy vs. the necessary dependency that AD creates to a greater and greater extent as the disease progresses. Thus, the book addresses not only best practices in the care and treatment of people with AD and their loved ones, but also inspires closer examination of traditional biomedical ethics so as to add substantively to the precision and applicability of the latter.

Issues of living wills, advance directives, substitute decision-making by surrogates, end of life decision-making, and best-interest approaches are also examined in light of the changing nature of the abilities of the person with AD to articulate for him- or herself