
Victims of Dementia

Services, Support, and Care

Wm. Michael Clemmer, MDiv, PhD



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SOME ADVANCE REVIEWS

“Offers hope for a better way of treating persons with dementing illness. It is straightforward enough to aid anxious family members as well as support professionals who counsel those families as they make hard decisions about how to care for a victim of Alzheimer’s disease. A no-nonsense, practical, yet warmly human book about how a group of professionals struggled to find a better way to help victims of dementia.”

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Beryce W. MacLennan, PhD

Clinical Professor

Department of Psychiatry

George Washington University



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ABOUT THE AUTHOR

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Foreword

We stepped off the elevator into a large hallway with a circle of chairs in its end, pictures along its walls, and brightly colored markings over its doorways. A cluster of older persons was sitting there, and Catherine Durkin greeted them warmly, introducing me as a visitor with interest in their "home." She turned to one well-dressed, brightly smiling woman, and asked if we could see her room. She replied, quite sincerely, "I'm sorry. They've taken it out for redecoration." Without any sense of ridicule, Catherine replied "Well, how nice. We'll find another room to see," and moved us down the hall.

It was my first visit to the then six-month-old Wesley Hall ministry at Chelsea United Methodist Retirement Home. As Bishop, I had been hearing of this work and its signal departure from care heretofore given to persons suffering from Alzheimer's disease. As we spent the next half hour among residents and staff, the unique character of provisions for "home" for this special population of persons became very clear. As we departed, we met the woman to whom Catherine had spoken as we entered. "Your room has come back and it is lovely," Catherine said. The woman smiled and went down the hall happily to find her place of residence.

The story is not told to make fun of the woman whose mind was so confused by the attack of a major illness. It is told to illustrate the accepting, careful way of relationship and residential care described in this book. A certain hospitality that accommodates the confusion of the moment without judgment, while at the same time providing secure space and support, is one of the goals that has been achieved by Wesley Hall and the ministries of elder care that have sprung from its beginning. Dr. Clemmer and Mrs. Durkin are two who deserve praise for a vision lifted which could be grasped by so many and now enjoyed by individuals and their families as the ravages of memory impairment and dementia overtake their lives. In his book,

Clemmer outlines the need, the philosophy developed to address the need, and the practical implementation of that philosophy in day-to-day reality.

While the book may seem more directed to providers of care for the elderly, its value is not limited to them. Anyone who has watched someone struggle to hold on to reality as the diseases of mind steal away the possibility of always knowing how to function, anyone who has struggled to understand what is happening to someone they love, anyone who has commitment to quality life provision for persons in need, will find information and encouragement from these pages. Insights into the nature of dementia diseases as well as glimpses of frustrations and confusions that attack care givers are helpful to a wide audience. To be sure, those with involvement in care-giving facilities will be well instructed by this work, both its general account of how a dream became a reality, and its detailed appendices that will function as a workbook for those who seek to establish a similar ministry.

Therefore, this book is a gift to a wide audience. It celebrates a linking of Christian concern for the elderly with the best knowledge and practice of medicine and social science. From these pages emerges a whole way of viewing and responding to a very particular audience of persons whose number is increasing and whose needs cry out for gentle and knowledgeable engagement. I found the book moving. It linked memory of my visit there, memories of stories of persons struggling to care for someone suffering from Alzheimer's, my own wonderment about what care might be available for someone I know if this disease should strike them, and my gratitude for the involvement of the Church in care for the elderly. As I read the story of an idea unfolding, I was caught up in the journey of trying this and learning that, beginning one way and having to go another, always wrapped in the unwavering commitment to doing something not done before, and doing it well enough to make it worthy of expansion and duplication. The ministry of Wesley Hall is well done; it has expanded; it is being duplicated. Lives fraught with fear and frustration are being held in knowing, patient, and freeing surroundings. Families burdened with anxiety about what to do are finding release and comfort in the time a loved one is given to live on Wesley Hall and its descendants.

In these pages are clues for those who are not yet at the point of needing the assistance of residential care for a member of their family, but are searching for how to be patient and helpful. Behind the philosophies that informed the work of Wesley Hall lie insights about the disease and the approach of caregiving that will be most freeing and enabling for a sufferer. The guidelines for nurses and the provisions for their own relief and mental health are appropriate for home caregivers. The insights about the illness and its ravages are informative for all who would be sensitive to this tragic part of human experience.

That the story has been written is important, not only for the additional learnings and ministries it may provoke, but that the persons responsible for this beginning might be remembered for a long while. Catherine Durkin, Michael Clemmer, and all the staff unnamed that began the work and now continue it, are truly to be named among the saints who reveal the redemptive kindness of God. As their story is read, I hope their work will become the center of a prayer of thanksgiving on the part of the readers as it has been in the hearts of all whose families have been touched and sustained by their work.

*Bishop Judith Craig
Resident Bishop
Michigan Area
United Methodist Church*

Preface

This book is written in order to chronicle the evolution of Wesley Hall. It is about an effort to both marshal and deinstitutionalize the resources of the long-term care environment in order to provide a quality of life and a quality of affordable care for the memory impaired and demented that cannot be achieved at home without extreme cost and superhuman effort for a family. Ahead lies a look at what has been tried on Wesley Hall, at what has worked and at what has failed; a look at what appear to be “right tracks,” and what appear to be “wrong turns.” Much attention will be given to the nuts and bolts matters that arise in operating something like Wesley Hall. The intention is to provide a description which, on the one hand, is detailed enough to provide basic “how-to” information for the institutional caregiver who is thinking of creating or who is in the early stages of operating a living area for the memory impaired and demented, and which, on the other hand, is in language plain and straightforward enough so that the material identifies important elements that will help family caregivers and other supportive professionals (physicians, social workers, clergy, and counselors) in the process of selecting an institutional environment of high quality for the memory-impaired and demented person who can no longer live at home.

Acknowledgments

I would like to express the deepest gratitude to Mrs. Catherine Durkin for her friendship and mentorship as she championed the development of Wesley Hall at the Chelsea United Methodist Retirement Home. She has been of great assistance in the preparation of this book. In particular, I want to thank Catherine and her daughter, Terry Durkin-Williams, for graciously giving me permission to use their training manual as the appendices to my description of the Wesley Hall project. Terry and Catherine assembled the manual in an effort to help other long-term care professionals to provide quality care for victims of dementing illness.

I would like to thank the Board of Trustees of the Retirement Homes, Detroit Annual Conference, Inc.; Mr. Elmer Benson (then Chief Executive Officer of the Retirement Homes); the staff; and the residents of the Retirement Homes for working together to make Wesley Hall into a reality.

I would like to thank the residents of Wesley Hall, as well as their families, for doing so much to shatter the horrible stereotypes about victims of dementing illness.

Finally, I would like to thank the people of The Haworth Press for the opportunity to bring the story of Wesley Hall to you.

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Chapter 1

A Christmas Eve

Snow had fallen the better part of the day and had painted a picturesque setting for Christmas Eve. Although it was only 5 p.m., it was already dark. I was going to drive Bob, a 66-year-old resident of the Chelsea United Methodist Retirement Home, to his daughter's so he could spend the holiday with her and her family. I did not mind doing the favor for Bob and for his family; it simply meant taking the more scenic two-lane highways home rather than the expressways.

Bob and I walked from the buildings of the Chelsea Home to my car, which was in the parking lot. The snow had tapered off; the night had turned crisp and clear. As we walked out to the car, we talked. I had offered to carry the bag which held his clothes, but Bob decided that he could manage it on his own. Bob liked to do as much as he could by himself. I unlocked the passenger side car door and Bob entered the car. I settled into the driver's seat and fastened my seat belt. I reminded Bob to fasten his own seat belt; he buckled up with only a little difficulty.

We drove away from the Home and out of the village of Chelsea. As we traveled, I was glad that I had agreed to take Bob home. The night was beautiful. Many of the farmhouses along the way were gaily decorated. Bob spoke of his life in New York State and how much he had enjoyed the winters there. We talked about cross-country skiing, snowshoeing, and running a trap line. Bob's memories and word-pictures seemed so strong and clear, like things that had happened only yesterday. The roads were snow-covered, so we did not make the fastest travel time. Rather than grouse about the weather, we enjoyed one another's company and the beauty of the snow.

We had to pass through the village of Manchester to reach Bob's family. The village has a lovely Christmas Eve custom in which many of the residents decorate the front of their homes with luminaria (paper bags partially filled with enough sand to hold up a lighted candle). They were almost everywhere as we drove down the hill into the center of the village. The light of the candles through the paper bags filled the night with an eye-pleasing glow. Bob could not remember seeing anything like it before. I think that the drive through Manchester helped Bob and I both feel more of the Christmas spirit; the remainder of the trip, we talked increasingly about Christmas.

We were about ten minutes from Bob's daughter's house when we began to talk specifically about Bob spending the Christmas holiday with his family. It was a difficult topic because Bob was a victim of memory impairment and dementia. He was confused about who he was going to visit, but he was good-natured in his confusion. Bob could not remember that he had a daughter, a son-in-law, or two beautiful grandchildren. In Bob's mind he (Bob) was under 30 years old and, as yet, unmarried. The best Bob could do was come to a feeling that he was spending the holiday with special members of his family. He thought that his daughter was his sister; he thought that his grandchildren were a niece and a nephew.

Fortunately, Bob was a person who maintained a mostly positive and cooperative demeanor despite his impairment; in contrast to Bob, many other victims of dementia sink into depression and/or hostility (verbally or physically lashing out) as their confusion increases and their cognitive ability decreases. The malady from which Bob suffered is not something new, or newly discovered. In the past, the problem has been called senility, organic brain syndrome, dementia, Alzheimer's disease, memory loss and an assortment of other names. What can be called new or different is a slowly blossoming change in medicine's and society's attitude toward the phenomenon of severe memory impairment and its impact on the victim, the victim's family, and the nation's health care system (particularly the long-term care/nursing home system). Since 1980, research into memory impairment and dementia has greatly expanded the pool of knowledge about the causes and effects of the problem. Among the most important insights that have been gained

is that memory impairment and dementia are primarily disease-related symptoms and not some aspect of the normal human aging process.

Sadly, the memory impairment and dementia due to Alzheimer's disease and related disorders has been found to be progressive and irreversible, inevitably resulting in death. Not just hundreds, but thousands of people, and soon, hundreds of thousands of people will suffer the effects of dementing illnesses; many of these people will require years of institutional care in a nursing home or other long-term care facility. Currently only a small number of long-term care facilities are willing and ready to provide care to the memory impaired and demented.

Many of the victims of a dementing illness will have families who will face the trials and tribulations of caring for them: the spouse, mother, father, or some other (usually older) family member who is becoming increasingly unable to live without substantial assistance because of memory impairment and dementia. The care of such an impaired person can become totally exhausting. Nancy L. Mace and Peter V. Rabins have aptly described the caregiver's job in *The 36-Hour Day*. Wandering, interruptive, repetitive, highly emotional, or violent behavior by the impaired person can create an extremely stressful life for the caregiver. Often families find that they are offered only two rather depressing options: either chemical restraint of the impaired person at home using heavy sedatives or chemical restraint of the impaired person and admittance to a nursing home. Families need to know what other options may be available to them and how to evaluate those options.

In Bob's case, his family had worked at coping with dementia; they had come to understand what normal behavior is for a person with dementia and they overcame enough of the difficulties of Bob's handicap to enjoy what would become their last Christmas together. Bob was able to participate in the opening of gifts, in the Christmas meal, and in the enjoyment of his family. They returned Bob to the Chelsea Home the day after Christmas and he settled back into the program of Wesley Hall (a special living area organized for people with memory impairment resulting from Alzheimer's disease and dementing illnesses). Bob did not remember