

Preface

VIRTUALLY EVERY DECISION TO SELECT A NURSING HOME, personally or by the family, is crisis-driven. People are desperate and often unable or incapable of spending the time and attention needed to find the best possible facility. Even those who are wary about nursing homes have to trust that they have chosen the best possible place for themselves or their loved one. Yet, families *should* be able to have faith in their decision, for nursing home care is guided and governed by public laws, regulations and standards that hold great promise. Moreover, America's national nursing home reform law (Public Law 100-203 in the *Social Security Act*) pledges specifically that *each resident* who lives in a nursing home is to receive quality of care, be afforded quality of life, and have specific rights and privileges maintained.

Fortunately, many people do select a nursing home that is meeting its contractual obligations so specifically laid out in law. Out of America's 17,000 nursing homes, in every state there are many nursing homes that strive daily to maintain public standards. Increasingly, many go even further and adopt and apply pioneering approaches that result in high quality care that is resident-directed and engages families and others in positive ways.

Distressingly, far too many nursing homes still fail to meet public standards. They provide, at best, mediocre care. Moreover, far too many fail miserably, and many residents in these facilities suffer needlessly from neglect and even abusive care. That is why the National Citizens' Coalition for Nursing Home Reform (NCCNHR) fought so long for this law in 1987. These persistent problems are why the national reform law directs state governments to inspect facilities and enforce standards.

Still, despite what the law directs, there are serious flaws in many state and federal enforcement programs. Too often, deficiencies go undetected and standards unenforced. In addition to the enforcement program another safety net is the national long-term care ombudsmen programs, prescribed in the federal *Older Americans Act in 1978*. Every state has established an ombudsman program. Ombudsmen, both paid and volunteers, visit facilities, listen to residents, help resolve their problems, and, with the resident's permission, refer serious complaints to the survey and inspection agency. Ombudsmen programs strive to provide education about nursing home care and the rights of residents. The work of the program is critical to help monitor nursing homes, as well as board and care, assisted living and other long-term care settings. In spite of this program's importance to residents and families, ombudsmen are often short on funds, time and volunteers to meet the critical needs.

NCCNHR and other advocacy groups around the country advocate daily for quality of life and care for residents in nursing homes. Our advocacy takes many forms. We monitor government regulatory activities and continually push for stronger enforcement of existing laws. We participate in government meetings to help drive decisions that are centered on the needs of the vulnerable, ill, and disabled individuals who require services. We provide public education and training for advocates and ombudsmen. We assist and respond to the media when it focuses on substandard nursing home care. Whenever possible, we work in collaboration with groups of health care professionals, providers and research scientists to advance the strongest possible standards and protections for residents. For example, because of the serious shortage of staff in nursing homes, we developed a minimum staffing standard that is supported by many organizations. And, we assist and work with family members, particularly in the development of strong, effective family councils.

Families are a critical component of the nursing home system of care. There is an essential role for family members in helping to obtain and maintain the quality of care and life for residents prescribed by law. This book guides families in achieving good care for residents in nursing homes.

The authors of *Nursing Homes: Getting Good Care There* are advocates, experienced professionals, who represent over one

hundred years of caring, concern, advocacy and knowledge about the day-to-day life of residents living in nursing homes. Three (Frank, Fraser, and Hunt) have served as state long-term care ombudsmen. One (Burger) is a nurse who has worked in nursing homes, a long-time advocate, and former NCCNHR executive director. Frank and Hunt have also worked directly for NCCNHR providing valuable work in policy development, advocacy and training. In this book, so generously donated to our organization, the authors provide a wealth of insights, information, and encouragement to help residents, family members, resident and family councils be advocates for change. Because it carefully describes the intent of the reform law and offers valuable ideas for care giving, the book will also be useful for nursing home staff and management and other professionals working to achieve quality care for residents.

NCCNHR is confident that your concerns about getting good nursing home care will be addressed in the pages that follow. You will be rewarded with improved care as you boldly and consistently apply the advocacy information and techniques provided in this valuable consumer guide. We hope that you will also become a part of NCCNHR's advocacy network by joining our organization, especially in its work to achieve our proposed standard for increased nursing home staffing. It will take all of us, advocates, ombudsmen, regulators, caring nursing home staff, health care professionals, *and you* to see that *each resident* receives the protection, services and benefits promised by law. It is the least we should expect for our elders and citizens with disabilities who need the care nursing homes are responsible for providing.

By Elma L. Holder, Founder
The National Citizens' Coalition for Nursing Home Reform