

## **Introduction: Why the Handbook?**

### **Purpose of the Handbook**

The purpose of this Handbook is to assist family members, non-profit corporations, or any friend of a **Medicaid**-eligible nursing home resident, or one who will need such eligibility in order to meet the costs of nursing home care, to ensure that the resident enjoys the protection of all of his or her legal rights as a citizen, a patient, and a consumer.

In the Handbook, we attempt to demystify the two areas of the law that significantly impact nursing home residents:

**Probate Court** Guardianship Law and Procedures

**Long-Term Care Medicaid** Rules and Procedures

This Handbook does not address political issues like the lack of a national policy for meeting the costs of long-term care for an ever-increasing frail elderly population or the societal values regarding how our country or Commonwealth should treat incapacitated elders. Rather, this Handbook offers a practical guide for those who want to roll up their sleeves and help individual nursing home residents to enjoy a quality of life, as best as their abilities will permit, in their homes. For nursing home residents, the long-term care facility is their home.

### **Who Should Read and Use this Handbook?**

This Handbook was written to assist any person interested in helping a **Medicaid**-eligible nursing home resident (1) who resides in Massachusetts and (2) who meets the following three criteria:

- does not have the mental capacity to understand the nature of his or her medical condition or the risks and benefits of any treatment proposed by a treating physician;
- has not executed a **healthcare proxy document** authorizing another person of his or her choice to make medical decisions regarding care and treatment when he or she becomes incapacitated and unable to understand the nature of his or her medical conditions or the risks and benefits of any treatment proposed by the treating physician;
- does not have a **Probate-Court**-appointed guardian to make decisions to approve or refuse recommended medical care and treatment.

## How Extensive Is the Problem that this Handbook Addresses?

Advocates estimate that there are thousands of Massachusetts nursing home residents who meet the above three criteria: They do not have the mental capacity to give “**informed consent**” to medical treatment, have no **healthcare proxy document** in which they have appointed an agent, nor do they have a medical **guardian** appointed by the **Probate Court** to authorize medical care and treatment. Every nursing home resident has the right to accept or decline medical care and treatment, and a medical provider who gives medical treatment without authority from the patient (or his or her proxy or guardian), except in emergency situations, is guilty of medical malpractice and violates the civil rights of the resident.

Despite the laws with respect to informed consent, many nursing home residents receive medical care and treatment every day without legal authority for the providers to furnish that care and treatment. Sometimes the nursing home staff relies on family or friends to obtain “authority” to provide care. Such persons are referred to as *de facto* **guardians**, who exercise power as if they had legal authority to do so. Such *de facto* guardians, however, have no legal authority. For some residents, there are no families or friends involved, and nursing home staffers provide care and treatment, which is usually quite appropriate medically but entirely illegal.

## Why Is this Problem so Widespread?

The widespread lack of adherence to the laws is primarily due to the lack of resources available to indigent nursing home residents. Residents with significant assets or income experience the benefits of the protections that a **guardian** offers, but indigents needing **guardianship** services are not so fortunate. Nursing homes operate on tight budgets, especially in difficult economic times. They are not compensated for the costs of filing for and obtaining guardianship or providing guardianship services to their residents. Facility administrators are either unwilling or unable to secure such guardianships and hope that they escape criticism for relying on *de facto* **guardians**.

## Have the Courts Addressed the Problem?

In March, 1999, the Supreme Judicial Court of Massachusetts in **Rudow v. Division of Medical Assistance** ordered the **Medicaid** Program (also known as **DMA** or **MassHealth**) to provide a mechanism to pay for guardianship services furnished to **Medicaid**-eligible nursing home residents. Although **Medicaid** promulgated regulations<sup>1</sup> that were designed to implement that decision, many nursing home residents continue to go without the guardianship services that our laws mandate.

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<sup>1</sup> You can read the regulations at **106 C.M.R. 520.026(E)(3)**. These regulations are directly relevant to a guardian of a nursing home resident and appear in Appendix 6-O at the end of Chapter 6.

## How the Handbook Is Organized

The Table of Contents outlines the sections of the Handbook. You may have already noticed that some words and phrases are in bold letters, which indicates that you can find the meaning of such words or phrases in the Glossary of Terms and Acronyms at the end of the Handbook.

Chapter 1 contains two case studies that describe typical situations when people need nursing home care and the problems and issues that must be addressed. The first case study is that of Agatha Adams, an unmarried woman who has been hospitalized and requires nursing home placement. The second case study involves a married couple, Mr. and Mrs. Knellson; Mr. Knellson is already a nursing home resident. Both individuals need to have guardians appointed by the **Probate Court**, as well as needing to secure **Medicaid** coverage to help pay the costs of their nursing home care. The case studies illustrate how the **Medicaid** rules for single residents and married residents differ.

Chapter 2 discusses the rights of nursing home residents. This Handbook uses the term “resident” and not “patient” because the nursing facility is the resident’s home. Residents should enjoy the same rights they enjoyed when living in their former homes in the community. Furthermore, federal and state laws and regulations provide rights specific to nursing home residents and address quality of life as well as medical and clinical issues.

Chapter 3 explains the duties of **guardianship**, a responsibility not to be undertaken lightly. A **guardian** is appointed by the **Probate Court** over the **ward** and must perform his or her duties by being responsive to the ward and to the requirements of the court.

Chapter 4 addresses a question that looms large for nursing home residents: How does the nursing home bill get paid? Finances are an important topic, and the chapter includes discussions of **Medicare**, “**private pay**,” **long-term care (LTC) insurance**, payments from Veterans Affairs (VA), and to the largest extent, **Medicaid**.

Chapter 5 describes **guardianship** laws and procedures and explains what a person must know in order to serve as **guardian** for a nursing home resident.

Chapter 6 discusses an actual **guardianship** petition and the documents needed to prepare for a **Probate Court guardianship** proceeding. The chapter also describes what to expect in dealing with the court system as the guardianship procedure unfolds.

Chapter 7 explains **Medicaid** rules and procedures.

Chapter 8 walks the reader through a long-term care **Medicaid** application, complete with application forms.

Chapter 9 offers some final suggestions for a **guardian** as he or she undertakes to provide crucial assistance to a nursing home resident to ensure the quality of life and dignity that we all hope for.

The Resources section contains selected resources that can assist a guardian in meeting the day-to-day responsibilities of that role.

The Glossary of Terms and Acronyms contains definitions and explanations of important words, phrases, and recurring acronyms. Terms that appear in the Glossary appear in bold type in the text of the Handbook.

This Handbook is designed to assist any person or public interest agency willing to step up and help a vulnerable person, namely, a frail elder who is not only sick, but unable to cope mentally and financially with his or her needs. Anyone willing to serve as a **guardian** for an indigent nursing home resident should be able to get the help, guidance, and assistance needed to do the job well.

Guardians will not only assure the rights of incapacitated nursing home residents; they will also improve the quality of life in the long-term care system as they help nursing home staff, **ombudsmen**, and **DPH** surveyors (inspectors) to meet their goal of seeing that the system works well for all.

A **guardian** should organize the affairs of the **ward** and maintain good medical and financial records. Maintaining a journal and using a checklist (see Chapter 9 for a suggested format) to keep track of important documents will help keep the guardian's thoughts organized, and make things run more smoothly.

A **guardian** should not be reluctant to seek counsel on issues grand and small. If the **ward** cannot help with information about his or her wishes regarding medical care, there may be other sources whom the guardian can consult: relatives, friends, or associates of the ward. At all times, the guardian must use the ward's values when deciding medical issues, whether they relate to minor treatment, surgeries, participation in research projects or studies, organ donations, or Alzheimer's research involving the post-mortem study of the patient's brain. The guardian's decisions must be informed by the perennial question: "What would be the ward's wishes if she or he could understand the current situation and speak to me about those wishes?" That is the challenge of the guardian: To enable the ward to enjoy life to the best of his or her capability and according to his or her own wishes.