

Handbook for Massachusetts Guardians



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I. PREFACE

The court has appointed you as **guardian**, with the power to make all health and personal care decisions your loved one is unable to. Now what?

How do you make health care decisions for someone else? What if the incapacitated person you have been appointed for wants to get married? Can he or she vote? Drive? What are your reporting requirements to the Court?

Serving as guardian can be difficult, time-consuming, and sometimes stressful. You may benefit from the support of family, friends or spiritual counselors, and also from various organizations that offer information, education, and support groups. The Alzheimer's Association, for example, offers some funds for respite services to provide caregiver breaks, information on support groups, and many books and pamphlets with helpful information.

We hope this Handbook will help you to understand your new responsibilities as guardian for an incapacitated person. While this Handbook is meant primarily for those who serve as guardian of adults, not minor children, the resources outlined in Chapter X will be helpful for guardians of minors as well.

This Handbook is not intended to be a substitute for the professional assistance you may need from an attorney, accountant, social worker, or other professional. It is intended merely to get you started – to provide a useful overview of your responsibilities and resources to find the help you need. Thank you for accepting this very important role!

II. RIGHTS OF INCAPACITATED PERSONS

- When a person is under full guardianship in Massachusetts, he or she loses many fundamental rights that we take for granted, such as the right to marry and the right to vote. The incapacitated person even loses the right to drive, subject to the approval of his or her guardian. Some incapacitated persons may have sufficient capacity to marry or vote, but the guardian would be required to obtain the court's approval prior to consenting to such actions.
- One of the primary goals of the Massachusetts Uniform Probate Code (MUPC) was to *limit* guardianship when appropriate, and to *avoid* guardianship altogether by respecting the wishes of the person to be protected if they had executed a valid Health Care Proxy or Durable Power of Attorney.
- In a further effort to protect persons in the guardianship process, court authorization is required for the guardian to make many major decisions for the incapacitated person – for example, to admit the incapacitated person to a nursing facility for long-term care.
- If the guardianship is limited, the incapacitated person retains all rights not specifically limited in the court order.
- A guardian can not deny the incapacitated person certain rights just because he or she is under guardianship, and should advocate for the incapacitated person to retain any rights they are able to.
- Whether a guardianship is full or limited, if the incapacitated person resides in a residential care home or nursing home, or other long-term care facility, the Patient's Bill of Rights and other state laws provide additional rights. These include the rights to privacy, to have visitors, to have telephone calls and to be free from non-therapeutic chemical and physical restraints. Depending on the protected person's situation, however, the guardian has the right to place restrictions on those rights. For example, the guardian could restrict undesirable visitors if they had a harmful effect on the protected person.

Even though the incapacitated person may lose many rights in the guardianship process, he or she retains many other rights. It is the guardian's responsibility to ensure that those rights are not violated.

Persons under guardianship always retain the specific right to:

- be protected against abuse and neglect
- be treated with dignity and respect
- a safe, sanitary and humane living, working and learning environment, which is the least restrictive environment for the protected
- privacy, including the right to bodily privacy and the right to private and uncensored communication with others by mail, telephone, or personal visits
- religious expression in the manner of his/her choice
- interpersonal relationships and sexual expression
- exercise control over all aspects of life that the court has not delegated to the guardian
- appropriate services suited to the incapacitated person's needs and conditions, including mental health services
- have the guardian consider the incapacitated person's personal desires, preferences and opinions, particularly in regards to ethic, religious and cultural values
- exercise the option to procreate
- equal treatment under the law, regardless of race, religion, creed, sex, age, marital status, sexual orientation, or political affiliations
- have explanations for any medical procedures or treatment, including information about the benefits, risks, and side effects of the treatment, and any alternative procedures or medications available
- have personal information kept confidential including withholding certain information the incapacitated person may not want his/her family to know
- notice of all proceedings related to the guardianship
- review personal records, including medical and treatment records
- speak privately with an attorney, ombudsman, or other advocate
- have the guardian available to meet the needs of the incapacitated person at all times
- *not* be involved in research projects
- continuous review of the need for full or partial restoration of rights
- bring a grievance against the guardian or request the court to review the guardian's actions

- petition the court to modify or terminate the guardianship including the right to meet privately with an attorney or other advocate to assist with this legal procedure
- request removal and replacement of the guardian, or request that the court restore rights if the incapacitated person has regained all or some capacity.

The guardian has a responsibility to request that the incapacitated person's rights be restored when there is evidence that he or she has regained capacity.

III. YOU'VE BEEN APPOINTED GUARDIAN – NOW WHAT? POWERS AND DUTIES OF GUARDIANS

You've been appointed guardian of a family member or friend -- now what? Well, it depends on whether the court **limited** the guardianship or not.

- If the court imposed a limited guardianship, you have only the responsibilities and authority outlined in the court order.
- If it is a plenary (full) guardianship, you will usually make medical and personal decisions for the incapacitated person, such as medical and surgical consents, rehabilitative services, recreational services and possibly residence.
- You, as guardian, have a responsibility to consult with the incapacitated person whenever possible and to the extent the incapacitated person is able to participate in the decision-making.
- You, as guardian, must act in the incapacitated person's best interest at all times, while making decisions as closely as possible to what the incapacitated person would if he or she were able to.

IN GENERAL, THE GUARDIAN MUST:

1. Provide a Copy of the Order (Letters) to Providers

- Provide a copy of the Order (Letters) appointing you as guardian to the incapacitated person's medical providers and any other persons who would need to know that you should be contacted in the event of an emergency or medical issue for the incapacitated person. For example, if the incapacitated person is a resident of a nursing facility, they must have the order on file.

2. File a Guardian's Care Plan

- You are required to file a Guardian's Care Plan within 60 days of appointment.
- In the Care Plan, you will provide the Court with basic contact information for you and the incapacitated person, describe the incapacitated person's present abilities and needs, anticipated future abilities and needs, state whether the incapacitated person has financial resources sufficient to meet his or her needs, whether the person's residence has changed during the reporting period, state the frequency of your visitation with the incapacitated person, describe the incapacitated person's ability to participate in decision-making, provide information regarding fees paid for guardianship services and fees paid to others for care, and other information.
- The court will issue an Order Regarding Guardian's Care Plan either approving the Care Plan, approving it with conditions, not approving it, or scheduling a hearing on the matter.
- After the first Care Plan, a Care Plan must be filed on an annual basis.

3. Secure Appropriate Residence

- As guardian, you will usually determine where the incapacitated person lives, with limitations. The incapacitated person should be allowed to remain in his or her usual residence as long as there are sufficient assets to provide the assistance necessary to make it safe and comfortable. In order to stay at home, most incapacitated persons require some assistance in connection with day-to-day living. This assistance can range from having

someone available to do simple errands to twenty-four hour supervision or nursing care.

- If you are not also the conservator of the incapacitated/protected person's estate, you will need to work in conjunction with the conservator to consult with community and social service agencies that serve individuals with your protected person's particular disability to ensure he or she receives any additional assistance that he or she is eligible for.
- If it is no longer possible for physical, mental, or financial reasons for the incapacitated person to continue to reside in his or her residence, it is the guardian's responsibility to find a new residence within the incapacitated person's means and arrange for the move.
- It may also be necessary to file for benefits such as Medicare, Medicaid, Social Security or SSI in order to assist with costs for residential placement.
- The guardian should maintain a relationship with an attorney to request court approval when necessary and for guidance when he or she is unsure whether court approval is required.

The guardian must seek court approval prior to moving the incapacitated person to a nursing facility.

- If a person with developmental disabilities cannot work competitively, he or she will be eligible for SSI and Medicaid upon turning 18. Those benefits will convert to Social Security and Medicare when the principal bread-winning parent starts receiving Social Security or dies, whichever comes first. Parents or guardians should contact the Social Security Administration in the month in which the person with disabilities turns 18. Because parents do not automatically continue to have legal authority when their child with disabilities turns 18, this is a good time to consider guardianship proceedings.

Even if the incapacitated person resides in a group home or care facility, the guardian must make sure he or she receives appropriate care and services.

4. **Maintain Involvement with the Incapacitated Person**

- As a general guideline, the guardian should visit with the incapacitated person at least monthly, and must attend quarterly care plan meetings if the incapacitated person is a resident of a nursing facility.
- The guardian must visit more frequently if necessary to address the specific needs of the incapacitated person.

5. **Make Health Care Decisions**

- If the incapacitated person executed advance directives such as a Health Care Proxy or Living Will prior to becoming incapacitated, these documents may provide guidance regarding his or her choices. A Health Care Agent will continue to have authority to direct health care decisions, unless the authority has been limited or revoked by the court.
- Unless otherwise specified in the court order, the incapacitated person no longer has the legal capacity to make decisions concerning his or her medical treatment and the guardian will have exclusive authority to make such health care decisions.
- However, the guardian should encourage the incapacitated person to participate in decisions concerning his or her health care to the extent possible. The guardian should strive to make decisions as closely as possible to how the incapacitated person would make them if he or she were able.
- Before making a decision, the guardian must know and understand the nature, purpose, consequences, risks, benefits, and alternatives to the medical decision requested. It is important to continue to use the health care providers the incapacitated person trusts and has used in the past if appropriate.
- If the incapacitated person suffers from a special problem such as mental retardation, Alzheimer's Disease, or alcoholism, the guardian should become more knowledgeable about such conditions.
- Certain decisions such as sterilization, experimental procedures, withholding

treatment, and other issues that require the court to make a substituted judgment determination will require prior court approval.

If the guardian is unsure whether court authority is necessary, the guardian should consult with an attorney and present the issue to the court.

6. Arrange for Programs and Activities

- As guardian, you have a duty to ensure that appropriate programs and activities are provided for the incapacitated person at the level that he or she can participate. Day and residential services for people with disabilities vary across the country, but you can get information about the services that are available from a local agency or government department that provides services to this population. For example, for an incapacitated elder, you might contact your local elder services agency or the Alzheimer's Association. There is a list of helpful resources at Chapter X.
- Determine what the incapacitated person likes to do. If he or she likes to read, make sure that reading materials are continually available. If he or she has hearing problems, make sure he or she has a properly working hearing aid. People with severely limiting disabilities enjoy being taken on periodic outings. Some organizations will make daily telephone calls to the incapacitated person and many churches have volunteers who will visit the incapacitated person on a regular basis.
- As guardian you are responsible for maintaining control over the incapacitated person. *If he or she becomes a danger to himself or others, you must take all reasonable steps necessary to reduce the danger.*

7. Make Funeral Arrangements

- It is advisable for the guardian to consult with the incapacitated person, family members, and the conservator of the estate to investigate and possibly pre-pay for the burial arrangements for the incapacitated person with his or her funds.

8. Court Authority Required for Some Treatment Decisions

- The guardian must obtain prior authority from the court before making some decisions on behalf of the incapacitated person, and would do so by filing a “Petition to Expand, Modify or Limit the Powers of the Guardian.”

Some of the decisions that the guardian must seek court authority for are enumerated on the form and include the power(s) to:

- consent to treatment with anti-psychotic medications or other extraordinary medical treatment;
- admit the incapacitated person to a nursing facility,
- revoke the Health Care Proxy;
- execute a Do Not Resuscitate or Do Not Intubate order, or authorize some other treatment or action (sterilization, withholding treatment, experimental treatment) for which a substituted judgment determination may be required.

9. Death of the Incapacitated Person

- When the incapacitated person dies, the guardian must notify family members.
- If the guardian is not also the conservator of the estate, the guardian must immediately notify the conservator. If the incapacitated person had a Will, the conservator should file it with the probate court in the county in which the person resided at the time of his or her death, and notify the person nominated as executor.

IV. TERMINATION OF GUARDIANSHIP

- A guardianship is terminated on the death of the incapacitated person, although the guardian should take the final steps of notifying the family and conservator and filing the Will (if in possession of it) with the Court as outlined above.
- A guardianship may also be terminated upon Petition to the Court if the incapacitated person no longer meets the standard for establishing the guardianship or, in other words, his or her mental capacity or physical ability is restored. The Petition must be filed along with a Medical Certificate for

Termination of the Guardianship which supports the incapacitated person's ability to receive and evaluate information or make or communicate decisions and that guardianship is no longer necessary.

- If the incapacitated person moves out of state, you should consult with an attorney to ensure that the proper protections are put in place in the new jurisdiction and to terminate the Massachusetts guardianship.

V. DEFINITIONS

GUARDIAN

- A guardian may be appointed for protection *of the person only*.
- Persons under guardianship are called "*incapacitated persons*."
- A guardian may be appointed for an incapacitated person "who for reasons other than advanced age or minority, has a clinically diagnosed condition that results in an inability to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance."

CONSERVATOR

- A conservator may be appointed **to protect property and business affairs** of a person in need of protection.
- Persons under conservatorship are called "*protected persons*."
- A conservator may be appointed for a person to be protected if "the person is unable to manage property and business affairs effectively because of a clinically diagnosed impairment in the ability to receive and evaluate information or make or communicate decisions, even with the use of appropriate technological assistance, or because the individual is detained or otherwise unable to return to the United States, and the person has property that will be wasted or dissipated unless management is provided or money is needed for the support, care, and welfare of the person or those entitled to the person's support and that protection is necessary or desirable to obtain or

provide money.”

FULL/PLENARY GUARDIANSHIP

- A full/plenary guardianship generally removes from an incapacitated person *all personal decision-making responsibility and authority*.
- Under the current law, clinicians and the Court must now consider whether an incapacitated person’s legal rights can be preserved in specific areas and whether the guardianship can be limited or tailored accordingly.

FULL/PLENARY CONSERVATORSHIP

- A full/plenary conservatorship generally removes from a person to be protected **all control over his or her assets**.
- Under the current law, the Court must now consider if a protected person’s rights can be preserved in specific areas and whether the conservatorship can be limited or tailored accordingly.

LIMITED GUARDIANSHIP

- The concept of limited guardianship allows the Court to address specific areas of incapacity and tailor guardianship decrees to meet an individual’s unique circumstances.
- Individuals may be competent for one purpose and not competent for another.
- Orders curtailing or removing an individual’s liberty should be made only to the extent absolutely necessary to protect the individual from harm.

The guardian must be aware of the scope of the guardianship to fulfill his or her responsibilities while respecting the incapacitated person’s rights.

LIMITED CONSERVATORSHIP

- Similarly, the concept of conservatorship includes both limited and unlimited conservatorships.

- A conservator should be appointed only when necessary, and then with only those powers that are necessary to address the individual's actual limitations. For example, if appropriate, a conservatorship may be limited or apply only to investments or real estate and leave to the incapacitated person the ability to receive pension income and pay for daily or monthly expenses.

The conservator must be aware of the scope of the conservatorship to fulfill his or her responsibilities while respecting the protected person's rights.

PROTECTIVE ORDERS

- In some cases, the Court may determine that a conservatorship is not necessary at all, but that a narrowly tailored protective order will suffice to protect an individual's assets/property.
- For example, the Court, without appointing a conservator, may authorize, direct or ratify any contract, trust, or other transaction relating to the protected person's property and business affairs if the court determines that the transaction is in the best interests of the protected person.

TEMPORARY GUARDIANSHIP

- While a petition for the appointment of a guardian is pending, if an incapacitated person has no guardian, and the Court finds that *an emergency exists that will likely result in immediate and substantial harm to the health, safety or welfare of the person alleged to be incapacitated*, and no other person appears to have authority to act in the circumstances, on appropriate motion, the Court may appoint a temporary guardian who may exercise only those specific powers granted in the Order.
- The appointment may be for a period of up to 90 days except upon a finding of extraordinary circumstances set forth in its Order, the Court may order an appointment for a longer period to a date certain.
- The Court may for good cause shown extend the appointment for additional 90-day periods.

The temporary guardian must be aware of the scope of his or her authority under the temporary appointment to fulfill his or her responsibilities to the incapacitated person while respecting the incapacitated person's rights and abilities.

TEMPORARY CONSERVATORSHIP

- While a petition for the appointment of a conservator is pending, if a person to be protected has no conservator, and the Court finds that an immediate and/or urgent situation exists that will likely result in substantial harm to the property, income or entitlements of the person to be protected or those entitled to the person's support, and no other person appears to have authority to act in the circumstances, on appropriate motion, the Court may appoint a temporary conservator who may exercise only those specific powers granted in the Order.
- The appointment may be for a period of 90 days except upon a finding of extraordinary circumstances set forth in its Order, the Court may order an appointment for a longer period to a date certain.
- The Court may for good cause shown extend the appointment for additional 90-day periods.

The temporary conservator must be aware of the scope of his or her authority under the temporary appointment to fulfill his or her responsibilities to the incapacitated person while respecting the protected person's rights and abilities.

SUBSTITUTED JUDGMENT

- When the Court finds that a person is incapacitated as a result of the individual's minority, mental illness, mental retardation, or inability to make or communicate an informed decision due to physical incapacity or illness, *the role of the court is to substitute itself as nearly as possible for the incapacitated person and to act on the same motives and considerations as would the incapacitated person.*

- The court's role as substitute decision-maker is *subjective* in nature; the goal is to determine with as much accuracy as possible the wants and needs of the individual involved.

The Court must answer the question - what would the incapacitated person decide if he or she was able to make the decision?

VI. RESOURCES FOR GUARDIANS AND CONSERVATORS

Following is a comprehensive list of information and resources to assist guardians and conservators in fulfilling their duties.

National Guardianship Association
(See Standards of Practice and Code of Ethics)
www.guardianship.org

Massachusetts Guardianship Association
www.massguardianshipassociation.org

Massachusetts Probate and Family Court
<http://www.mass.gov/courts/courtsandjudges/courts/probateandfamilycourt/>

Entitlements

www.Massresource.com
Commonwealth of Massachusetts
www.800ageinfo.com
Administration on Aging
www.aoa.gov

Diseases:

Amyotrophic Lateral Sclerosis (ALS) – Lou Gehrig's Disease
www.alsa.org
Huntington's Disease
www.hdsa.org
www.ninds.nih.gov
Multiple Sclerosis
www.nationalmssociety.org
www.ninds.nih.gov/disorders/multiple_sclerosis
Muscular Dystrophy
www.mdausa.org

Massachusetts Commission for the Deaf and Hard of Hearing
www.mass.gov/mcdhh

Parkinson's Disease

The American Parkinson's Disease Association,

www.apdaparkinson.org

APDA, Massachusetts Chapter

www.apdama.org

Stroke:

American Stroke Association

www.strokeassociation.org

National Institute of Neurological Disorders and Stroke:

www.ninds.nih.gov

National Stroke Association

www.stroke.org

National Heart, Lung and Blood Health Information Center:

www.nhlbi.gov

Diabetes:

National Diabetes Information Clearinghouse

www.niddk.nih.gov

Geriatric Mental Health and Disease:

Geriatric Mental Health Foundation

www.gmhonline.org

Massachusetts Chapter of the Alliance for the Mentally Ill

www.namimass.org

Dementias:

Alzheimer's Disease:

www.alzheimer's.org

www.alzfdn.org

www.alz.org

Binswager's Disease

Multi-infarct Dementia

Wernicke-Korsakoff Syndrome

www.nimds.nih.gov

Lewy Body Dementia

www.lewybodydementia.org

Pick's Disease

The Association for Frontotemporal Dementia

www.ftd-picks.org

Developmental Disabilities:

Association for Retarded Citizens (ARC)

www.thearc.org

Massachusetts ARC

www.arcmass.org

The ARC of Greater Boston

www.gbarc.org

Massachusetts Assistive Technologies Partnership

www.matp.org

New England INDEX Information on Disabilities Exchange

www.disabilityinfo.org

Rehabilitation Research and Training Center on Aging with Developmental Disabilities

www.nic.edu

Caregiving and Support Information:

American Association for Retired Persons (AARP)

www.aarp.org

Grandparents Caring for Grandchildren

www.aarp.org/grandparents

Professional Resources

Elder & Disability Attorneys

Massachusetts Chapter of the National Academy of Elder Law Attorneys

www.manaela.org

Geriatric Care Managers

National Association of Professional Geriatric Care Managers

www.caremanager.org

Geriatric Care Managers of New England

www.gcmnewengland.org